



BORN TOO SOON, TOO SMALL, TO DIE — A PLEA FOR A FAIR INNINGS

Johan Smith, Clarissa H Pieper, Gert F Kirsten

In this 50th anniversary year of the Universal Declaration of Human Rights (UDHR) it is appropriate to call for fairness in the allocation of resources to prevail on behalf of extremely-low-birth-weight (ELBW) infants weighing between 800 and 1 000 g or of a gestational age (GA) of 27 - 28 weeks. The Writing Group for the Consortium for Health and Human Rights recently invited institutions that teach and train health professionals to explore and embrace the link between human rights and health.¹ The UDHR, of which our government is a co-signatory, states that all people are born equal in dignity and rights and that these rights are guaranteed to everyone. Yet in medicine, dignity and equality appear to be neglected or unevenly protected.¹

While developing countries such as South Africa acknowledge the UDHR, they do not universally adhere to it. Cost-



Johan Smith did his undergraduate training at the University of Stellenbosch, and specialised in paediatrics there in 1987. In 1990 he did a Fellowship in Neonatology at the Catholic University of Leuven in Belgium. He registered as a neonatologist in 1994 and is currently a consultant in neonatology at Tygerberg Hospital. His main interests are neonatal pulmonology and intensive care.

After undergraduate training at the University of the Orange Free State, Clarissa Pieper specialised in paediatrics at Stellenbosch in 1988. She registered as a neonatologist, then did a BSc Hons in epidemiology and statistics and an MSc in epidemiology in 1997. She is currently a consultant in neonatology at Tygerberg Hospital, with particular interests in community aspects of neonatal care and neonatal infectious diseases.

Gert F Kirsten did his undergraduate training and specialised as a paediatrician at the University of Pretoria. From 1978 to 1981 he worked in paediatrics and neonatal intensive care at Red Cross War Memorial Children's Hospital and Groote Schuur, and from 1984 to 1986 did a Fellowship in Neonatology at the Hospital for Sick Children in Toronto, Canada. He obtained his MD in 1996, and is currently Head of the Neonatal Intensive Care Unit at Tygerberg Hospital.

containment policies and birth and/or gestational age-based rationing programmes discriminate against ELBW infants in terms of access to neonatal intensive care (NIC).

As a result of limited financial and physical resources for health care, delegates at the 10th Conference on Priorities in Perinatal Care in South Africa, held during 1991,² agreed to limit or withhold treatment of ELBW infants ($\leq 1\ 000$ g or of a gestation ≤ 28 weeks) admitted to State hospitals. We estimate that this practice has resulted in more than 2 244 ELBW infants dying within 3 days of birth on an annual basis in South Africa. Improved ante-, peri- and postnatal care, as well as perinatal

survival rates of ELBW infants over the past decade, call for reassessment of this policy. We examine the potential impact on survival rates, NIC costs and quality-adjusted life-years (QALYs) gained should all ELBW infants (between 800 and 1 000 g) in South Africa have access to NIC. We also present a hypothetical model that could serve as a decision framework for the provision of care to these infants.

SURVIVAL RATES OF ELBW INFANTS

The medical profession recognises that a child may be born alive substantially earlier than 28 weeks; this is reflected in countless reports and is evidenced by thousands of live and growing children. The survival of ELBW preterm infants has improved dramatically over the last two decades. Based on the remarkably improved Japanese survival rates, the definition of the viability limit in the Eugenic Protection Act in Japan was amended in 1991 from 24 to 22 completed weeks of gestation.³ Actuarial survival (future life expectancy from a given postnatal age) in a large cohort of inborn premature infants below 30 weeks' gestation in the USA improved from 88% at birth to 98% on day 28 of life.⁴ At 26 weeks', 27 weeks' and 28 weeks' gestation, the survival rate to discharge was 75%, 85% and 90%, respectively.⁴

In South Africa, weight-specific survival rates from birth to discharge in State hospital NIC units vary between 32% and 66% for infants weighing between 750 and 1 000 g.^{5,6} Recent unpublished data from Tygerberg hospital show 70% survival rates for infants in the 750 - 1 000 g weight category born to pre-eclamptic mothers (D Hall — personal communication).

The authors acknowledge that there are pitfalls in drawing conclusions from hospital-based statistics and that large discrepancies exist in our country in relation to available facilities and policies followed. The present situation also results from the perceived scarcity of resources as much as from the inheritance of their previous misallocation.

The survival rate of infants at the threshold of 'viability' is improving, creating considerable confusion in the minds of the



public and in those who act as health care policymakers, but who are not well informed. Improving the knowledge base is of great importance since decisions with regard to the allocation of resources and the provision of health care should take outcomes and effectiveness of treatment into account.

THE NATIONAL DILEMMA — THE NEWBORN INFANT AND THE CONSTITUTION

The Bill of Rights of the 1996 Constitution of the Republic of South Africa does not mention the newborn infant.⁷ Instead, it refers to 'the child', meaning 'any person' under the age of 18 years. In Chapter 2 (Section 28(1)(a)), the Bill of Rights states that every child has the right to a name and nationality from birth, but fails to define whether such a child acquires that right before or after a particular GA. We can therefore conclude that the concept of the newborn infant as an individual with rights is poorly defined.

THE NEWBORN INFANT AND STATUTORY AND PUBLIC OBLIGATIONS/LAW

The Births and Deaths Registration Act (Act 51 of 1992) defines a live birth as the presence of breathing attempts, without referring to a specific GA, whereas the registration of a death is required after 26 weeks' GA.

THE DILEMMA FACING NEONATOLOGISTS

Our estimations of the national effects of rationing took the following into account: (i) that the total number of births in South Africa in 1995 was 809 439; and (ii) that national birth weight distributions and birth weight-specific survival rates of ELBW infants would be similar to those in our area and to local rates of survival if intensive care was offered.⁸ Low-birth-weight rates in southern Africa vary between 13% and 22% (average 17%).^{9,10} An estimated 0.7% of the total number of births (5 666) could be ELBW infants. If 60% of ELBW infants require NIC, and 66% survive (2 244), then the total estimated annual 'cost' amounts to R45 million (R670.00 per patient per day, surviving in the NIC unit (NICU) for an average of 30 days).¹¹ This relates to 0.001 - 0.002% of the total health expenditure for 1997/98 (R22.7 billion). An evaluation of the ELBW numbers shows that 0 - 1 infants in the Western and Eastern Cape, Mpumalanga, Northern Province and Free State require admission to an NICU per day, whereas 2 infants per day require access in Gauteng and KwaZulu-Natal.

An analysis of the number of infants requiring treatment suggests that the provision of intensive care may save 1 additional infant for every 7 infants treated.

An additional problem at present is the nationwide shortage of intensive care facilities for newborn infants. The authors acknowledge that existing facilities would have to be upgraded

and that additional units would have to be built in some areas (KwaZulu-Natal, Gauteng and the Eastern Cape) to accommodate all the infants who require NIC. These costs were not taken into account in this commentary. This shortage is exacerbated by a shortage of qualified NIC nurses.

In summary, a national birth weight-based rationing programme that denies intensive care to infants below 1 000 g saves 0.001 - 0.002% of the national health budget — at a human 'cost' of approximately 2 244 lives per year.

ECONOMICS OF THE NICU

Neonatal intensive care of infants weighing 800 - 1 000 at birth results in a paradox, i.e. increased survival rates, increased costs for their care, and severe neurodevelopmental impairment in 10 - 15% of cases.¹² NIC results both in the largest gain in survival rates compared with other weight categories (19 - 43%), and the largest economic loss for any weight subgroup.¹²

The significant gain in survival rates should be reason enough to suggest a shift in the balance of resource allocation to benefit these infants. In the presence of scarcity, resource allocation should be based partly on the patient's ability to benefit from intensive care and partly on the risks and costs involved. At no other time during life does intensive care result in such improved survival rates. In the discussion under the heading 'The dilemma facing neonatologists' we concluded that 7 infants would have to be treated to save 1 additional infant. Although this would raise the cost, it has been shown that non-survivors die within 48 - 72 hours of birth, therefore consuming limited intensive care resources.^{4,13} Infants weighing less than 1 000 g at birth account for 30% of the total expenditure of a particular unit and cost approximately R350 per QALY gained.¹⁴ QALYs reflect how much it costs for a particular activity or intervention (NIC) to take a number of people with a disease state to a state of health over time, i.e. it brings together quality and length of life in a single measure. This concept can be used to prioritise and compare health activities.

Where does NIC rank compared with other programmes that save lives? From Table I it is evident that NIC compares favourably with other health care interventions. Any intervention or programme that costs less than \$35 000 per QALY is judged by some societies to be cost-effective and worth implementing.¹⁵ Although direct comparison of health care services between South Africa and the USA or UK may be inappropriate, it nevertheless gives a good idea of the 'ranking' of NIC. QALY reasoning is, however, not without flaws. Health care (medicine) should be cost-effective, but this argument fails to consider moral and ethical issues.

In order to decide on the economic value of NIC of ELBW infants, the economic value of other health interventions would



Table I. Quality-adjusted life years (QALYs) gained for specific conditions

Condition	Year	QALY (\$/year)
ELBW (500 - 999 g) ¹²	1983	22 400
IDDM*, intensive management ²³	1997	20 000
Intracoronary 'stents' ²⁴	1997	23 600
Hypertension treatment ²⁵	1997	14 - 27 000

* IDDM = insulin-dependent diabetes mellitus.

need to be assessed using similar methods. Cost-effectiveness studies need to compare the cost of a programme with the lifetime benefits of the programme. Here we have a problem, since estimates of lifetime benefits are not readily available for ELBW infants.

'Being born too small, too soon' may not be the main issue, since the largest expense appears to be related to the salaries of the attending personnel, which constitute 47 - 80% of the total NIC expenditure.^{14,16}

THE 'WORTH' CONCEPT

Economics, more than ever before, is now the driving force behind health care. How do individuals prove their worth or value in order to justify their price? Do we, in South Africa, regard individuals as inherently valuable and of equal social worth? As neonatologists and advocates for the newborn infant, we believe in what we are 'selling'. We have vast experience and scientific data to justify our 'business', but how do we prove that our 'product' (the surviving ELBW infant) is a 'bargain' to society? How do we tailor the benefits in terms of quantity of lives saved and quality of life years gained to the State or society's expectations? How do you translate society's values into resource allocation decisions?

The authors suggest that a hypothetical model (Fig. 1) may serve as a basis to illustrate the 'worth' of an infant compared with that of the mother to the State. The diagram suggests that in terms of the State's reasoning, the mother's worth at the beginning and end of her pregnancy is a hypothetical 100%. To illustrate the 'worth' of the fetus during pregnancy we used local gestational age-related survival rates. We argue that during the first half of pregnancy the developing human infant is of little 'worth' to the State. However, the 'worth' of the fetus increases rapidly and in linear fashion, reaching a critical threshold at 65% of full term (27 weeks' GA). At this point we argue that the infant's chances of survival in a South African NICU exceed the chance of dying if provided with that care. In terms of economics, value-based 'selling', we feel that the 'client's' worth to the State is accordingly 60 - 70% that of the mother (the State's maximum value), and since he/she now has a greater chance of surviving (albeit with life-supportive

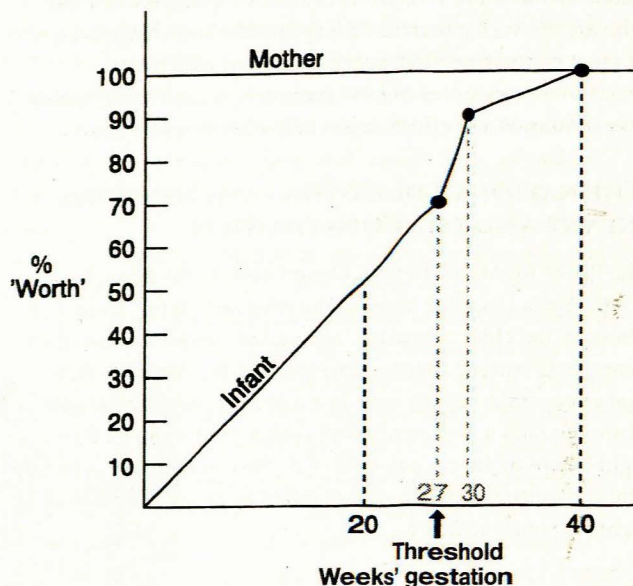


Fig. 1. The 'worth concept'. Graphical representation of the duration of pregnancy (x-axis) and the 'worth' of life (y-axis). The mother and her fetus vie for their worth as pregnancy progresses.

treatment) than dying, the State has to act as arbitrator. We argue further that this critical threshold is the stage of objective viability from a South African public sector perspective. The provision of life-supportive management at this point is beneficial in terms of curing the most likely pathological condition, i.e. lung immaturity. The threshold of ≥ 27 weeks' GA (≥ 800 g) is also the point at which the chances of long-term normal neurodevelopmental outcome exceed the risk of handicap. It is also important to note that probably less than 2% of serious handicap is accounted for by very preterm delivery, compared with a much higher percentage attributable to birth asphyxia.¹⁷ In other words, meaningful life expectancy, quality of life and social worth outweigh the potential burden.

NIC AND DISCRIMINATION

In a recent issue of this journal the Editor wrote: '... the present cuts have been too sudden and too deep, ... and to leave indigent South Africans without access to care beyond primary and secondary levels. Sadly that would further deepen the already scandalous chasm in our two-tier system, and create a situation where the politicians and other well-to-do continue to be able to get their heart valves and hips replaced, but not the poor.'¹⁸

A programme or policy of limiting or withholding NIC from ELBW infants increases the racial disparity of perinatal and neonatal deaths already existing in South Africa. It blatantly discriminates against particular social groups (the poor and the uninsured), undermines the already questionable autonomy of



the newborn, intrudes on the patient-physician relationship and imposes untenable moral-ethical dilemmas on physicians and nursing staff alike.

Poverty is often compounded by race, with rationing resulting in disproportionately more coloured and black infants dying than their white counterparts.¹⁹ Racial differences in neonatal deaths are partly related to a higher proportion of low-birth-weight infants among coloureds and blacks compared with whites, inherited inequities in health care provision, and our present health care system. The deficiencies in our health system are further highlighted by the significantly better survival rates among ELBW infants admitted to certain private neonatal intensive care units when compared with State-funded units. More than 80% of ELBW infants with respiratory distress syndrome (RDS) survive private NIC.²⁰ Stolz *et al.*¹³ recently concluded that NICU cost-containment plans vested in birth weight-based rationing are ineffective, and that denial of NIC treatment should rather be based on the condition of the infant and perhaps the concerns of the family. There is no need to deny the ELBW infant access to NIC if we follow a 'first come, first served' policy, or we could stop weighing infants at birth or estimating GA. This reasoning would, however, result in increased pressure on physicians who would have to limit the admission of bigger infants, who in turn have a better chance of survival.

WHAT DO WE PROPOSE?

This commentary was written in an attempt to stimulate debate, to improve the knowledge base of decision-makers, to highlight the growing dilemma of trying to meet increasing demands for services within financial constraints, to highlight the conflicting ethical issue of individual rights, and to stimulate public involvement in decision-making relating to resource allocation. We accept that the provision and funding of water, sanitation, education, electricity, primary health care and programmes aimed at reducing preterm delivery could have a greater impact on public health than financial outlay for the provision of intensive care.

The authors would nevertheless like to suggest that the State accept its responsibility to provide universal care for ELBW babies born at or after 27 weeks' GA. Objective data and reasoning have been presented to support this proposal. We feel that at the present time it is reasonable for neonatologists to set a threshold of birth weight and GA above which it is advisable to apply life-supportive/saving technology universally. Like Rosenblatt,²¹ we acknowledge the discrepancy between our ability to care for individual patients and our failure to address the problems of larger society, but call for further exploration of the 'fair-innings' principle that entitles every ELBW infant to an equal start to life.²² If an equal start to life is denied, then the delivery of intensive care will continue to be at risk of rationing, based either on an individual's ability to pay, or on conditions or characteristics other than those of

the underlying medical problem. This, as we all know, would further increase the gap in our existing two-tier health service.

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RATIONING VERSUS EQUITY — THE SOUTH AFRICAN DILEMMA

Alan D Rothberg, Peter A Cooper

The article by Smith *et al.*¹ has appeared at an interesting and challenging point in time, one that juxtaposes a 'plea for a fair innings' from a trio of committed neonatologists who invoke the Universal Declaration of Human Rights, against proposals for a regulated minimum set of hospital services to which all South Africans will be entitled.² The latter recognises current South African realities and seeks to create an awareness of the methodologies of resource allocation according to prevalence and severity of disease, effectiveness of treatment, and cost. In contrast, Smith and his co-authors generally fail to recognise some harsh South African home truths.