
The Ethics of Life and Lives in Neonatal Intensive Care

Kyra Landzelius

Abstract

This essay examines a recent ethical debate concerning the motives driving biomedical intervention for humans born ‘too soon’, at the lower ‘limits of viability’. Via open letters published in an international neonatology journal, physician-practitioners and parents of preterm babies enacted a heated discussion regarding decision-making rights and responsibilities. The debate raised conventional bioethical issues: questions about whether to initiate, withhold or withdrawal aggressive life-support; about authority, agency, accountability; about resource allocation. The debate also evinced meta themes regarding the ‘quality of life’ as lived experience, versus the ‘value of Life’ as abstract principle. In working towards a more enlightened ethics, we must candidly weigh the failures as well as the successes of biomedicine on the frontiers of human survival.

On the edge of viability

Nature’s metronome for human gestation clocks a timetable of 38–40 weeks ‘womb time’ for our species. Newborns who deviate from this schedule to arrive early (and accordingly unfinished) re-present spatial and temporal anomalies, and are identified as such when science christens them ‘preterm’. At present, biomedicine has fair chances (50/50) of keeping alive a preemie who comes into the world at 23 weeks’ gestational age—nearly half the normal maturational calendar. Survival for these youngest of babies teeters on a vulnerable threshold, which is officially termed the ‘limits of viability’. Birth that hovers at the threshold of viability brings with it a galaxy of techno-scientific challenges, to be sure; but equally so it brings ethical conundrums, public debates, tough policy choices, and political, moral and religious questions concerning some tricky practical matters and even trickier epistemological ones.

This essay examines a recent debate concerning the ethics of responsibility and decision-making at the lower limits of viability. In so doing,

it skirts a range of robust questions that suffuse what is becoming a perennial discussion about the proper 'role' of techno-scientific medicine as an interventionist strategy in the metamorphosis of 'normal' human being (as conventionally constituted) and in constructions of personhood relational with this being. My analyses focus on discerning the discourses and rhetoric regarding matters of accountability (multiply-conceived) and costs (social, financial and human) that arise in, through and because of neonatological care. In mapping the coordinates of this debate, this exercise does not aim or presume to give answers, rather it seeks to query the current historical conjuncture where the values of techno-science meet the values of life and the exigencies of living.

A gauntlet is thrown

The debate was launched by a controversial 'letter to the editor' submitted by the retired neonatologist, William Silverman, and published in the international journal *Pediatrics* in September 2004. Silverman was himself a somewhat controversial figure in the field. Although he was widely recognized as an accomplished clinical practitioner in his day, his post-retirement writings met with a mixed reception at best—marked, as many were, by critical interrogation of 'biomedical hubris' in general and neonatology's excesses in particular, especially its pursuit of aggressive intervention at the 'edge of viability'. In characteristically unapologetic style, Silverman's open letter calls for a 'national inquiry' to evaluate whether 'opportunism [has] overwhelmed compassion in the American neonatal intensive care industry' (2004, 403). Not surprisingly, given its suggestions of impropriety and profiteering no less, Silverman's provocation had a ripple effect: it sparked animated discussions amongst professionals and generated a modest flurry of rejoinder letters, some of which were published in a subsequent edition of the journal. It is of interest that alongside healthcare practitioners, a number of parents of preterm babies felt compelled to send commentaries, thereby interjecting their voices and experiences into what is typically an endogenous and delimited arena of professional knowledge productions. A closer look at the direction and tenor of the

Pediatrics debate reveals it to be a 'microcosmic' encapsulation of many of the key issues and dilemmas regarding intensive neonatological practices for and upon the extremely premature born. These include: problems of evidence, problems of voice, pervasive experimentation, the persistence of probability and ambiguities, and perennial questions regarding authority, accountability and agency.

Problems of evidence

One particular letter of note came from the neonatology division of a 'large inner-city, not-for-profit hospital' in Texas (Whitfield et al. 2004, 1371). This rejoinder is suffused with a tone of indignation regarding what the authors view as Silverman's veritable charge of a 'tacit conspiracy' (among neonatology physicians and nurses) to 'fund ailing departments of pediatrics'. They nonetheless concede that 'many' of the infants at the lower limits of viability 'have very prolonged stays in the hospital' (thereby tacitly acknowledging the large financial transactions underlying such care). The authors welcome Silverman's call for a national debate or even formal inquiry, yet insist—in an attack on Silverman's argument as being based on 'speculation, innuendo, and partial truths'—that any such inquiry must be fact-based and use 'good data': '[i]n an era of evidence-based medicine', they write, 'this is the very least we owe the public we serve' (ibid., 1372). Exemplifying this commitment to scientifically-sanctioned evidence, they cite statistics to support the case for aggressive intervention. They declare themselves 'very encouraged' by a recent article concluding that '66% of infants of 23 weeks' gestation are either normal (52%) or mildly to moderately abnormal (14%)' (ibid.). They further celebrate a 52% survival rate achieved at their hospital for infants hovering around the limits of viability, many of whom (it is asserted) 'survive neurologically intact' although they also admit that there is 'ambiguity' concerning long-term outcomes (ibid.). With these statistical figures in mind, we might pause here to scrutinize the logic of evidence-based medicine and its applicability at the limits of viability. Badenoch and Heneghan (2002, 1) summarize the evidence-based model in a five-step approach: (1) asking answerable clinical questions; (2) searching for the evidence; (3) critically

appraising the evidence for its validity and relevance; (4) making a decision, by integrating the evidence with clinical expertise and the patient's values; (5) evaluating one's own clinical performance. Heavily buttressed by probability theory (in keeping with scientific methodologies), this protocol for clinical decision-making clearly relies upon both deductive and inductive reasoning. While in theory applicable to most any clinical case (i.e., any given patient), the time-intensive, hermeneutic and reflexive formulas of evidence-based medicine arguably reduce or delimit its modeling under certain conditions, including conditions not atypical for neonatology hovering at the threshold of viability. Situations problematic to the implementation of evidence-based techniques might conceivably entail emergency medical events requiring split second decisions in the heat of a critical 'life-or-death' moment (for example, concerning whether or not to resuscitate an infant for the umpteenth time). The evidence-based model is also confounded when patients present with multiple and possibly synergistic disorders; these complicate prognoses, compound the 'answerable clinical questions' that might be asked, and reduce the likelihood of finding 'relevant' evidence (a neonatal patient on full life support might, at any given moment, suffer neurological insults, physiological imbalances, opportunistic infections and so on). Essentially non-measurable and incomparable phenomena that engender little to no 'evidence'—and are hence non-generalizable—further problematize evidence-based methods (such is especially the case regarding the assessment of long-term cognitive 'functioning' following brain haemorrhages, the effects of which are virtually unforeseeable, given the inchoate status and developmental plasticity of the neonatal brain). In further considering how preemies can render moot the logistics of evidence-based medicine, it bears note that 'being preterm' is not necessarily a 'disease' *per se*; rather it is primarily a state of immaturity that precipitates radical systemic instability in and of itself, whilst heightening the newborn's vulnerability to extraneous insults: these include not only infectious micro-organisms, but equally include debilitations directly consequent to the negative and unintended effects of many therapeutic interventions themselves. Accordingly, it might be said that the biggest challenge to evidence-based medicine arises from the preemie patient population's multiple resistances to predictive assessment, leading to the

not-much-better-than-chance 52% ‘normality’ rate that the Texas authors herald as science in action. Arguably more so than most medical specialties, neonatology confronts—head-on—a perennial philosophical problem of the scientific method, one that still over-shadows scientific certainty and plagues decision-making: the ‘problem of induction’ raised by the 18th century philosopher, David Hume. The skeptic Hume introduced uncertainty about the very rationality of the scientific enterprise by doubting that *matters of fact* (based, by definition, upon *past* observation and experience) could be used to reliably generalize beyond a limited set of data in order to predict *future* scenarios. As he saw it, science is based on the unproven assumption that resemblances can be taken for granted; in rejecting this assumption Hume reaches the conclusion that ‘the ultimate causes of the phenomena we observe are beyond the reach of human inquiry’. Hume’s challenge to inductive science—a challenge that has never been fully addressed nor refuted—undermines the very base of evidence upon which evidence-based neonatology would presumably rest.

Problems of voice

Yet another hitch with regard to implementation of the evidence-based model in neonatology concerns its call to recognize patient’s values. This laudable prescriptive obviously loses momentum when the patient is a newborn baby incapable of voicing opinion. By necessity, the patient’s voice is deferred to others: family members ‘naturally’ step into this space, but so do hospital ethics boards, legal arbitrators, academic bio-ethicists, and not least, medical practitioners—who arguably are allotted greater decision-making powers precisely in response to the patient’s silence. There is solid consensus in neonatological corridors that in order to make decisions commensurate with their values (not to mention in synch with ‘good science’) parents must be informed; a job that invariably falls to physicians, or secondarily to nurses or social workers. In the opinion of the Texas neonatal team, statistical information is sufficient to justify a ‘thoughtful and informed discussion about prognosis and delivery-room plans for resuscitation with parents’ (Whitfield et al. 2004). At their hospital, the reader learns, discussions with parents are guided by ‘a

threshold-of-viability guideline developed 10 years ago in conjunction with [the hospital's] institutional ethics committee'. Parental guidance was summarized in the sentence: 'We address the ambiguities at 23 and 24 weeks' gestation and allow parents, once informed of our hospital's statistics for survival and the uncertainty of long-term intact neurologic outcome, to give an advance directive for comfort care only' (ibid., 1372). Presumably wizened in matters (of ambiguity and uncertainty) and in clinical statistics for survival, 'informed' parents are thereupon 'allowed' to make decisions about whether to encourage doctors to do everything in their power to intervene in the infant's survival or whether to petition for withdrawal of mechanical life-support. Yet, we might well query: what is meant by 'ambiguities' and how it is that these can be 'addressed'? We might well ponder just what such pedagogy means for mothers and fathers in a moment of crisis and shock, the mother herself likely hospitalized or a recent patient? We might equally wonder how 'informed' decisions about the fate of one's flesh-and-blood child can be made on the basis of statistical abstractions? Adopting an historical stance and cultural distance, we might trenchantly inquire: how has it come about that a mother (or father) can be expected to weigh the statistics of 50/50 survival for her child?

In closing their rejoinder letter (with its blanket rejection of Silverman's indictment), the Texas team emphasize that, for each 'disappointed parent' that Silverman quotes in his provocative letter, 'our neonatal intensive care unit (...) can line up as many satisfied and grateful parents' (ibid). There are unattractive connotations, I find, lurking in this statement; connotations the gist of which amplifies upon critical interrogation of the operative logic of this closing argument—that the population of contented parents is at least equal to that of the discontented. By extension, is it implied that satisfied 'customers' somehow 'cancel out' dissatisfied ones, leaving a net gain, a summarily positive equation? Arguably, this move to a numbers game simultaneously (and via a suspect but all-too-cozy alchemy) spotlights and unabashedly promotes success stories and happy endings, whilst decentring the dissenters, the casualties, the failures, the unfortunate 'price we must pay'—those unhappy parents and their (potentially suffering) children ranked second to the miraculously and superlatively

normal, the miracle babies ‘saved’ at the frontiers of techno-science. Even what might be good faith attempts to give a balanced picture or ‘even the score’ (an understandable aim, given the negative slant of Silverman’s accusations) devolve toward a kind of medical lottery—perhaps by dint of the hope/myth of the perfect child and consummated parenthood, perhaps by dint of the seductive ‘progress narrative’ that underwrites Science, perhaps due to an erasure of biomedical failings (...) ? On neonatology’s own terms it seems the best yardstick at our disposal is one that marks differential values for life. When we encounter the hardships of disillusioned mothers and fathers whose hopes and lives have been devastated by an unlucky turn at medical roulette (such as those we will encounter in parental narratives quoted below), we might question the justice, sensitivity or even sensibility of comparisons. This is especially so given the essential incommensurability, not only of radically different ontological states, but even of the outcomes of infant-patients who share broadly similar conditions. These are profound and problematic matters indeed; and I am by no means suggesting that the neonatology team from Texas proposes easy answers or is guilty of naivety or deception in posing its rejoinder. My objective is merely to draw attention to the discursive framing, the affective management, if you will, of their commentary, with its petition for medical evidence, its unwavering faith in mathematics, its gravitational pull towards heroics and optimism. A somewhat more outraged path characterizes the second rejoinder letter we will consider; this one also in the form of a professional commentary that enters the ‘opportunism or compassion’ debate.

Pervasive experimentation

The most defiant and dissenting letter came from two leading neonatology physicians, both at the University of Virginia, who lambasted Silverman for presenting ‘a jaundiced view’ that skews data and consequently depicts ‘the glass 10% empty’ instead of ‘90% full’ (Kattwinkel & Boyle 2004, 1846). Arguing that ‘there are many more normal children who are alive and well because of the care provided to the highest-risk neonates’, they pose the impossible question: ‘How many normal children are we willing

to sacrifice in order to prevent one case of cerebral palsy?’ (ibid.). In the corridors of neonatology it is indeed an oft-heard refrain (and a plausible scientific ‘truth’) that life-saving advances proceed largely by means of aggressive interventions with and upon the ‘highest risk neonates’ born at the lower limits of viability. That the gestational age ‘boundary’ for viability has shifted progressively earlier over a near century of medical intervention (with the shift notably accelerating over the past four decades, once neonatology consolidated its ‘modern form’ [Landzelius 2006]) is a testament to neonatology’s extraordinary accomplishments in the care and survival of precocious, precariously ill newborns. This remarkable science has brought about indisputable chronological gains in the youngest of preemies that can be ‘saved’. Nonetheless, the odds of survival and the normality/abnormality ratio have tended to change little at the extreme limits of viability: for 23-weekers, survival hovers around 50% and the normality/abnormality ratio maintains a 1 to 1 correlation; the odds in both cases are roughly equivalent to chance. In short, then, whilst neonatology’s governance at the lower limits of viability has been characterized by steady temporal shifts in the average age of the patient population, this momentum has not necessarily been isomorphic or concomitant with meaningful improvements in gross outcomes (i.e. survival, ‘normality’) for the cohort of youngest patients on the (ever-moving) border of viability. Such statistical markers imply that the edge of viability has long been the frontier of experimentation, and that it continues to be so (as well, we might add, as being the frontline of the whims of fortune). The manifold costs (societal, economic, human) of this 50/50 experimental thrust—neonatology’s historical trend of ‘guess work’ at the threshold of viability—are worthy of critical reflection. For we have here—built into the ambitious frontlines as well as the everyday operations of a healing science and its clinical encounters—a set proportion of ‘rescued’ and ‘lost’ patients; a constant and largely equivalent percentage of ‘winners to losers’, so to speak: the satisfied parents the Texas team can ‘line up’ against the dissatisfied. In aggressively pushing the parameters of artificial life support and driving the limits of extra-uterine gestation, it seems business as usual to assume a steady stream of ‘guinea pigs’; business as usual, one might say, to take prisoners. This has become an acceptable path towards progress in neo-

natology; and is perhaps the only path. Yet if the neonatologists from Virginia had posed their difficult question thus: ‘How many “abnormal” children with sacrificial parents should we assume in order to secure one case of normality?’—it would be no less rhetorical and equally as impossible. It might however, highlight a different perspective. From this angle, it is remarkable that there is virtually no *sustained* professional ethical debate about the unimproved odds; and little by way of reflective interrogation of the clearly experimental praxes, habits and mindsets construed. 50/50 survival at the lower limits of viability has been naturalized into neonatology and its undertaking; with relatively few questioning the justness, let alone the repercussions, of this state of affairs. Silverman’s controversial call for a national inquiry into the motives that drive neonatology stands as a clear exception; one that prompted even the indignant authors from Virginia to acknowledge that ‘certainly there are abuses of the system and those who have profited excessively from making inappropriate clinical decisions’ (although they nonetheless are not compelled to support a national inquiry into the extent of such abuses or how best to protect against them [Kattwinkel & Boyle 2004, 1847]). Yet, as the discussion above has sought to query: it is not only the inappropriate, but verily the *appropriate* decisions and decision-making processes that warrant healthy scrutiny. Such is basically the stance adopted by the physician and professor John Lorenz, a prominent neonatologist who also felt compelled to pen a rejoinder to Silverman’s provocative editorial.

Persistence of probability and ambiguities

Lorenz joined the debate by proclaiming Silverman’s focus on opportunism to be narrowly ‘misguided’. Lorenz expressed deep resentment—yet not necessarily rejection—of the possibility that ‘the relatively aggressive care provided to extremely premature infants in the United States is driven by the lucrative reimbursement on which academic pediatric departments depend for fiscal solvency’ (2004, 403). In lieu of such a line of inquiry, Lorenz advocates directing attention to the deliberative processes of ‘how decisions to withhold or initiate and continue or withdraw intensive care are made at gestational ages at which the benefit/burden of aggressive neo-

natal care is questionable' (ibid.). Citing an American Academy of Pediatrics advisory, Lorenz puts forth the declaration that it is 'well established' that parents are the 'rightful decision makers'. Assuming this laudable (if in practice not consistently endorsed) premise, the real issue in his opinion is to better assist parents to make 'informed' decisions consistent with their values, such that parents can eventually be 'at peace' with whatever decision they make. This is hampered at present by the dearth of data regarding the medical counsel that parents receive, its factual as well as emotional dimensions: 'To what extent', Lorenz writes, 'do [physicians] meaningfully convey the possible ranges of qualities of life and ramifications thereof that may result for their infant and their family?' (ibid., 404). He underscores the need for more research into: the influence of the counselling physician's attitude (e.g., whether pessimistic or optimistic); the 'accuracy' of prognoses conveyed and the future quality of life scenario that any given counselling physician presents in any given case; the risk that counselling physicians are overly directive (whether inadvertently or no) in guiding parental decision-making.

In sum, then, Lorenz spotlights the central role of parents as (rightful) decision-makers, and emphasizes the ethical responsibility on the part of doctors to provide parents with accurate, neutral, unbiased information representing 'state of the art' medico-scientific expertise. Yet the presumed existence (let alone delivery to parents) of what might be deemed a 'fair' assessment of medical facts is implicitly called into question, it can be argued, by Lorenz himself. In his concluding query, he asks, 'What are the implications of the observation that *different treatment options* may be offered to parents by different physicians under *very similar clinical circumstances*?' (ibid., 404, emphasis added). What indeed? The implications for neonatology (its clinical practices and scientific reputation) lead away from universalism and absolute scientific truth-claims, and point in the direction of contingency, multiplicity, discrepancies, alternatives; of variance and translation in local practices. The implications for parents point squarely to matters of integrity and agency: if there are few 'hard facts' and significant variance in interpretation, then the question might be raised as to whether parents can ever be 'informed' decision-makers? A double bind threatens: parents are incontrovertibly reliant upon Expert knowledge, yet such knowledge

is demonstrably fluctuant as a matter of the expert's opinion, subjectivity, custom and/or whims.

To discern the main thesis of Lorenz' editorial proves problematic: for what are we, too, to make of 'the implications of the observation' that, in the space of a one-page commentary, he sings the refrain for more accurate presentation of 'the facts'; yet in his concluding note admits the wide discrepancy in actual presentation of facts under similar situations? It is just such involved scenarios and multi-factorial clinical encounters—such intricate and complicated decisions concerning phenomenological, physiological lived events—that inextricably characterize neonatology and challenge its mission. Here, the limits of viability meet the limits of neonatological knowledge; and in this encounter, the routine scaffolding of medico-scientific rationalizing is shaken at its very foundations. Lorenz' query is itself a rather convoluted way of acknowledging the significant breadth of 'expert' knowledge productions in clinical circumstances, even (or arguably especially?) at the edge of viability, the current 23 week boundary of human 'extra-uterine' survival. His 'observation' concerning variability in expert advice and practices under similar clinical conditions has been evidenced by numerous retrospective (broad-based comparative) studies as well as by programmatic studies (e.g. questionnaires regarding attitudes or practices, or surveys based upon hypothetical cases). Such studies have found treatment strategies and interpretations to not only vary between individuals, but to pattern along national, cultural and regional lines; variability becomes increasingly pronounced as one approaches the 'limits of viability'. Despite its roundabout mode of presentation, we might say that Lorenz' observation in point of fact stands as close to a 'fact' (i.e., a testimony about variance, the role of subjectivity, the persistence of uncertainty) as one is likely to come in the uncharted (unchartable?) terrain of diagnosis and future prognosis for the frail and sickly too-early-born. Indeed it is tempting to argue that uncertainty marks an inextricable guiding principle in the navigation of unruly scientific probabilities. Uncertainty carries multiple and situation-specific constraints, options, implications and resolutions, assuredly. Moreover there are cases—namely those less fortunate cases—when uncertainty slips resolution altogether: it escapes closure, or makes a mockery of it by installing instability, dis-

ability, lifelong handicap, 'special needs' care-giving. It is just such tragic forfeitures of hope that have prompted some parents to come forward and interject their perspectives into the 'opportunism or compassion' debate: finding in Silverman's challenge an impetus to voice their opinions. In point of fact, a greater number of rejoinder letters came from parents with disabled children than from healthcare professionals.

Perennial questions

The parents' letters published by *Pediatrics* brought to life personal odysseys that poignantly relayed the experiences of 'preemie parenthood'. Despite its irreducibly singular tale, each odyssey nonetheless echoed the others in its 'less-than-happy-ending' tenor and its sad tone. A mother of two disabled premature children (the survivors of a triplet pregnancy delivered at 25 weeks' gestation) reviews the litany of difficulties: from the overall lower quality of life (little opportunity: to 'nurture relationships with family and friends', to pursue a career, to have a normal 'night out'), to the substantial economic burdens (high costs of therapy, of special-needs equipment, of insurance coverage, etc.), to the enormous toll on families (with divorce rates at 85% and a constant 'fear that the marriage might crumble') to the emotional burdens, including chronic and almost unbearable agony about the future ('who will advocate for my children when I am gone?'), to the callousness of a society (which 'does not know how to react', encourages mothers to 'get over it' and 'get on with life', and fails to allocate sufficient resources to the disabled) (Van Hoven 2004, 896–897). Exposing the discrepancies and collective failures that operate between abstract ideologies about 'the value of life' and the paucity of public programs that might meaningfully enact such values, this mother writes: 'We have been told all of our lives that life has value, that our children have value, but society does not value our children (...) Society and the medical profession cared about keeping [my children] alive, they did not care about their lives' (ibid.). This commentary articulates a recurring theme among parents of special-needs preemies, regarding what they see as a discriminating and hypocritical gap that separates effusive rhetoric about 'life' (its sanctity, integrity, 'value') on the one hand, from, on the

other hand, concerted investment in infrastructures to enable all individuals (including not only disabled peoples, but families overwhelmed with the tasks of care-giving for them) to live with dignity and accorded respect regarding frailties as well as capacities and potentials.

The experiences of one distraught and angered parent (the father of a 23-weeks' gestation baby) led him to feel 'deceived and manipulated' by physicians with regard to 'outcomes of such infants in general and of my son in particular' (Vila 2004, 897). From this father's perspective: 'The neonatologists put [my son] through months of painful experimental treatment; caused him severe iatrogenic [medically-caused] disabilities; generated more than 1 million dollars in medical bills, and created a lifetime of pain and stress for him and his family (...) Our emotional, physical, and financial resources will continue to be sucked into an ever-expanding black hole of medical need' (ibid.). Vila underlines the role of iatrogenic disorders: a reference to disorders directly attributable to the biomedical healing regimen itself, to therapeutic procedures and their (known and unknown) detrimental effects. To reference iatrogenesis is to expose the structural fault line of therapeutic risks, a fault line to which neonatology is acutely susceptible. It is of significance to our story that one of the darkest chapters in neonatology's history resulted in a lifetime of blindness for substantial numbers of premie children treated with high-pressure oxygen—the disastrous impact of which was recognized a full decade too late. This unfortunate episode implicated (and undoubtedly influenced) a young William Silverman—none other than the *enfant terrible* of neonatology and author of the controversial open letter that sparked the debate concerning us here. The case of retrolental fibroplasia (iatrogenically-induced blindness caused by oxygen pressure rupturing the immature eye) gives us the most notorious, most tragic example of the trial and error method gone awry and drastically failing the community of afflicted it strove to cure. 'Trial and error' is still a cornerstone of interventionist strategies at the edge of viability; and the burden of iatrogenesis still falls disproportionately on premie parents, as the following saga makes clear. With still 15 weeks of pregnancy remaining, Kristina Fallon found herself in the delivery room—immanent mother to a 25 weeks' gestation baby. Fallon—whose letter joined the *Pediatrics* debate because

she felt she ‘must include [her] voice on this topic’—wrote in to protest: ‘I was never asked if I wanted my child “saved” (...) [and] even when things looked bleak, our doctors refused my request for a “do-not-resuscitate” order’ (Fallon 2004, 897). She continued: ‘this was not a teaching hospital, but the doctor told me: “We learn from children like this”’ (ibid.). Her experiences evince how far experimentalism (and the logistical scaffolding upon which it rests) has become naturalized and even routinized in neonatological thinking and doing. Whilst experimentation may represent a defensible, inevitable, even laudable *modus operandi* at the lower limits of human post-gestational survival, it comes with costs: not least, the substantial economic toll that the latest equipments and prolonged hospitalization exact. As her candour makes explicit, Silverman’s concerns about opportunism are echoed by Fallon: ‘I feel the hospital was only interested in money’, she unfortunately concludes (ibid.). Here, the cloak of experimentation meets (unwittingly or no) the crass reality of hospital budgets and budgeting—the very equation Silverman sought to interrogate in his call for a national inquiry into the motives driving aggressive intervention in US neonatology.

Conclusion: revamping bioethics?

So how are we to judge this controversial matter; what is the best way forward? It is of interest that in this debate unfolding via ‘letters to the editor’, we find a recital of conventional bioethics: questions are raised about accountability, authority, agency; about resource allocation and distribution; about starting or stopping life-support; about rights and responsibilities. We can also discern ‘meta’ themes that frame and inform the debate: themes regarding the ‘quality of life’ versus the ‘value of Life’; the moral mission to ‘save lives’ at odds with the omission of societal priorities to respect lives as lived. In seeking to map our way through this complex labyrinth towards an initial clearing, it seems evident that we need new ethical tools alongside new technologies—tools that can account for uncertainty as a diagnostic principle, and for experimentation as a therapeutic protocol. We need an ethics that truly accords parents re-

spected agency, alongside practitioners. If we as a society are to *collectively* mandate and pursue aggressive interventions at the lower limits of human viability, we need to equally distribute the burdens (as well as share the credits). A first step in this realignment would be to *collectively* insist upon social welfare for people with disabilities (and for their caretakers). The rhetoric and assignment of 'rights' must be balanced with the burden of share of responsibility.

References

- Badenoch, Douglas and Carl Heneghan (2002), *Evidence-Based Medicine Toolkit*, London: BMJ Books.
- Fallon, Kristina (2004), 'Compassion or opportunism? [Letter to the Editor]', *Pediatrics* 114 (3): 897.
- Kattwinkel, John and Robert Boyle (2004), 'Is the glass 10% empty or 90% full? [Letter to the Editor]', *Pediatrics* 113 (6): 1846–1847.
- Landzelius, Kyrá (2006), 'The incubation of a social movement? Preterm babies, parent activists, and neonatal productions in a U.S. context', *Social Science and Medicine* 62: 668–682.
- Lorenz, John (2004), 'Compassion and perplexity [Letter to the Editor]', *Pediatrics* 113 (2): 403–404.
- Silverman, William (2004), 'Compassion or opportunism? [Letter to the Editor]', *Pediatrics* 113 (2): 402–403.
- Van Hove, Maureen B. (2004), 'Compassion or opportunism? [Letter to the Editor]', *Pediatrics* 114 (3): 896–897.
- Vila, Brian (2004), 'Where there is no shame, there is no honor (Ethiopian proverb) [Letter to the Editor]', *Pediatrics* 114 (3): 897.
- Whitfield, Jonathon, Dianne Charsha, Shadin Hilton, Ashley Ring, Pam Sprague, and Iris Torvik (2004), 'Compassion or opportunism? [Letter to the Editor]', *Pediatrics* 114 (5): 1371–1372.