

AIDS, ANENCEPHALY, AND AHP: THE EFFECT OF MULTICRITERION MODELING AS A CATALYST IN BIOETHICAL DECISION MAKING.

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Abstract: The Analytic Hierarchy Process (AHP) has been advanced as both a concrete application of modern decision theory and a methodology using mathematical methods to assist in conflict resolution. As an aid to decision making, it is assumed to facilitate resolution through problem simplification, but not to fundamentally alter patterns of problem definition and analysis. It may be, however, that where problems have been stated with bivalent assumptions that the introduction of a multicriterion model using a judgment matrix in fact changes problem definition and operative assumptions. This appears to be the case, for example, in the construction of an AHP model addressing the medico-legal issue of the degree of care which should be given to anencephalic infants. This paper reviews that model and demonstrates how AHP-based multicriterion logic served as an active agent facilitating problem analysis, suggesting new resolutions.

Introduction

Medical decision makers regularly face ethical dilemmas that seem intractable. Is abortion a simple act of preventive health care, or is it murder? Is allowing a terminally ill patient to die without life-prolonging medical intervention an act of compassion or a dereliction of moral duty? Would the answer be different if one *helps* the patient to die? How can one choose between groups or individuals requiring scarce organs for transplant (Koch, 1996)? At what point does "quality of life" become untenable? Choosing between lives to save and those to let die, when to offer care and when not, when to deny a request for life support and when to insist on it: these are commonplace ethical quandaries which continue to elude resolution by medical professionals and society in general.

We believe these dilemmas persist not only because of a clash of personal and societal values, although that is an important factor, but also because society has traditionally viewed them from a logically constrained perspective. Either actively or through inherited and institutionalized decision-making rules, perhaps more by unconscious default than by intention, society has assumed that questions like those posed above have yes-or-no, either/or answers. Reliance on bivalent approaches has coincided with, and contributed to, the assumption of mutually exclusive categories into only one of which the subjects of our ethical uncertainty must be placed. A patient must be either alive or dead, human or non human; a fetus is either living or non living, and the abortionist either a killer or a moral provider of health care. Such partitioning of the human experience into discrete and disjunct categories leads to a "tyranny of taxonomy" (Gould, 1982) that severs multi-dimensional structures, dichotomizes meaningful nuances, and denies a very human kind of uncertainty. It also leads to several types of paradox, which are by definition insoluble in that form (Atikin, 1974; Kosko, 1993).

This paper argues that we can extricate ourselves from many of the ethical, often paradoxical thickets choking much of medical and medico-legal decision making. Two things are needed. First, we need to view the categories and attributes defining such bioethical decisions as overlapping ranges on a continuum rather than as discrete and disjunct sets. We also need to understand that cases may belong to more than one category simultaneously. Second, we need a way to operationalize these notions. In particular, we need a non-binary form of measurement that can accommodate multiple, intangible attributes, represent people's values, and elucidate the significance of value disagreement. The remainder of the paper shows how to accomplish these tasks.

To illustrate the change in perspective required by the first desideratum we review a landmark legal case concerning the issue of whether or not to maintain life-support for a severely anencephalic infant. Anencephaly is a rare disorder occurring when an infant is born without a brain but with a functioning brain stem, allowing for autonomic reactions including breathing, grasping, sucking, etc. In that discussion we deal with the

question of what constitutes "humanness," and its subset "personhood," arguing that these are multivalent rather than bivalent concepts. For the second requirement, that of measurement, we propose and illustrate the use of the Analytic Hierarchy Process (AHP) to demonstrate that personhood can be measured and that human cases exhibit different degrees of it. These findings fulfill a crucial need underscored in the legal cases cited. The significance and potential of this approach to bioethical dilemmas is the focus of the concluding section.

In the Matter of Baby K

In denying a hospital's request for permission to discontinue ventilator support for a severely anencephalic child, Baby K, Virginia District Court judge Mr. Clyde Hilton ruled in 1993 that, "Just as an AIDS patient seeking ear surgery is 'otherwise qualified' to receive treatment despite poor long-term prospects for living, Baby K is 'otherwise qualified' to receive ventilator treatment." (In the matter of Baby K, 1027) Individuals deserve care, in other words, irrespective of the deficit they may suffer or the prognosis they may face. Any other course, it was held both here and in another case (In re T.A.C.P, 588-589), would create an unacceptable category of living individuals burdened with a set of diminished human rights.

In the Matter of Baby K has come to symbolize for legalists and ethicists the bioethical, legal, and moral dilemmas created by a host of modern medical technologies which may artificially prolong existence in a variety of situations. Is the severely anencephalic infant like any other, and therefore equally qualified to all treatments necessary to prevent the material deterioration of an individual's condition (Weiss, 1994; Merola, 1994)? Both the court's decision and its myriad ramifications have been viewed by many as intuitively, ethically, and legally unsatisfactory. Thus ethicists and lawyers have returned again and again to the case, both as an ethical dilemma in its own right and as one of a class of problems for which no generally acceptable resolution has been found (Glover and Rushton, 1995; Goldberg, 1995).

Intuitively, we know there is a difference between an anencephalic child and an adult with a life-threatening disease. The neighbor down the street who gives our children candy on Halloween, the organist at our church who also sings at neighborhood parties, the woman next door who was so kind when we were ill: all seem very different—and somehow more worthy—than an anencephalic child who will never think, never love, never remember a fireworks display shared by the neighborhood on Independence Day. That neighbor or friend may be ill with a disease almost guaranteed to shorten his or her life. But in the interim, the man or woman who is ill, whether with AIDS or an inoperable cancer, is part of our interlocking, interrelated world. He or she is part of our lives, a human being who experiences and shares the world in ways an anencephalic child will never know. That person, whatever the disease, is a partner of precedence, of history, whose participation extends into our immediate and at least near-future worlds.

To argue an equality between the severely anencephalic child and the adult with AIDS (and by extension those with other life-threatening and debilitating disorders) may do violence to our sensibilities, but it is consistent with both long established principles of equity and justice, and with the laws that follow upon them. At the very heart of our justice tradition (Kittay and Meyers, 1987) is the insistence that no distinction be made between humans who are assumed to be equally vested with an identical packet of legal, moral and social rights, including the right to equal levels of health care and maintenance. Whatever their level of physical dependence or cognitive dysfunction, however great or small their degree of social contribution, every individual is guaranteed the opportunity to equal treatment (Brock, 1992). If an individual is deemed alive, prognosis is irrelevant. From this perspective, severely anencephalic children are *a priori* no different, no less worthy of our care, than adults battling AIDS, cancer, or any other disease.

Bivalence

The vast literature which has arisen around the specific issue of anencephalic care—and more generally, the question of when care should be discontinued in cases of medical "futility" (Spielman, 1995)—has focused on, first, whether or not the patient is to be considered living, and secondly, that patient's "quality of life." Obviously, the latter is dependent on the former. Just as the abortion issue has turned and turned again on when a fetus becomes a living, human being endowed with rights and protections, so too, in this area, the fundamental question involves the definition of living personhood and a possible category of living non-personhood.

The line between living and dead is drawn differently by different researchers. Should whole-brain or higher-brain standards be used in distinguishing between the living individual and the clinically dead patient whose

rights may be assumed to have terminated with his or her cognitive life? The former requires cessation of all brain function, including brain-stem activity. The latter requires only demonstrable cessation in the upper portion of the brain that severely anencephalic infants are born without. Those who believe in "whole brain" criteria have argued passionately that anencephalic infants are alive, are human, and should be so treated (Byrne, Evers, and Nilges: 1993; Sytsma, 1996, 21). Lack of higher cerebral function alone does not qualify as "brain death," they argue (Byrne and Nilges: 1993).

Another set of responses to the general questions raised by *In the Matter of Baby K* insists a resolution can be found through application of "quality of life" definitions. In general, these suggest that some people may be defined as alive but unworthy of maintenance because the quality of that existence is unacceptable. In 1995, for example, the American Medical Association approved the use of severely anencephalic infants as "living" organ donors on the basis of their unacceptable quality of life (AMA Issues, 1995: American Medical Association, 1995). This approval, however, is at variance with court decisions like *In re T.A.C.P.*, where a parental request for their child to be used as a living organ donor was denied on the grounds it might create a class of breathing "non-humans" without elemental rights (*In re T.A.C.P.*, 588, 9). Further, agreement on what constitutes acceptable quality of life is no clearer than criteria defining the dividing line between living and non-living. Researchers have shown, for example, that many may choose to live with medical restrictions (ventilator support, for example) that attending physicians perceive as defining an unacceptable quality of life (Sovsey, 1992; Gerhart, McLain, Lowenstein, and Whiteneck, 1994; Young, Marshall, and Anderson, 1994).

The failure of these traditional approaches was recently underscored by reportage of cases of "persistent brain death," a diagnosis describing bodies maintained for up to three years through aggressive medical intervention despite the complete lack of either neocortical or brain-stem function (Spike and Grenlaw, 1995). With strong parallels to Baby K, in one case a boy with no brain or brain-stem function was aggressively kept alive at the insistence of a parent. Was he a living individual with severe disabilities, or a dead body artificially maintained in a state approximating physical life? Would cessation of active interventions have been murder of a human, or simply the recognition of a state of human non-existence in the context of physical function?

There are no clear lines, no simple resolutions which will satisfy all parties. At issue are social definitions and socio-legal self-definitions which by their very nature are not amenable to bivalent analysis. These are problems of shading and degree. In reviewing this material it was clear that in every area—clinically, legally, and ethically—the problem resulted from a bivalent classificatory system of mutually exclusive classes. Any model must therefore first address the gray area between either/or in the arenas of degree and partial membership in a set.

Humanness

In modeling this problem we decided to accept *a priori* that anencephalic and others with extreme cognitive deficits are alive. We also began with the acknowledgment of the humanity of subjects with severe cognitive deficits. Baby K was more than a court case's name, she was an infant her parent fought for. To some, this would be reason enough to assume humanness (Nelson, 1995; Sytsma, 1996, 22). More practically, assuming the humanness of all was a prerequisite for defining a model which might address the general issues raised by Judge Hilton's original decision. It allowed us to leave the bivalent and apparently unanswerable question of when life begins or ends and focus on the problem of how to describe the difference we may perceive between people with radically different abilities and interpersonal histories. How did Baby K and an HIV-positive adult differ? Assuming both are "alive," if suffering from conditions which will decrease long-term life expectancy, are they in all ways equal? To make conceptualization easier, the "otherwise qualified" HIV-positive adult was given a face. We decided to use Arthur Ashe, Jr., an historian and athlete who contracted AIDS from a blood transfusion, as the case to compare with Baby K.

Unlike the living/dead, person/not person frame of the standard bivalent debate, this perspective allows a discussion of degree, and thus demands a multivalent approach. The goal then became to describe a claimant's degree of humanness, such that differences between claimants could be discussed without denying the humanity of any. As a goal we used degree of humanness rather than its subset, personhood, to emphasize the general characteristics which might be used to evaluate an individual. Although some treat humanness and personhood as synonyms (Dennett, 1975), the rationale for our decision to make personhood a subset of humanness will be discussed in a later section of this paper.

There is a broad literature based on personhood and humanness to assist in these determinations. For the sake of simplicity, we choose Joseph Fletcher's well known essay on humanhood as our starting point (Fletcher, 1979). Although it has been well discussed in the more than fifteen years since its publication, it remains a critical starting point for the modern conceptualization of what we mean—socially, neurologically, and biologically—when we talk about ourselves as a species. Since the question is the degree to which patients are human, and thus under the law's protection, Fletcher's short list of fifteen positive attributes of "humanhood" offered a convenient frame for our model. The question became, then, not the specific suitability of each criterion in Fletcher's model, but more generally whether judgments based upon characteristics constituting a general definition of humanness could transform this debate from the unresolvable tension of polar opposites stemming from a framework of bivalent definitions—yes /no, either/or—to one which might offer the possibility of consensus and agreement.

A Humanness Model

While it is based on Fletcher's work, and that of others, justifying this particular set of attributes is not our primary concern here. While the acceptability of a model in any given circumstance will clearly depend on the criteria chosen, the essential point we wish to present remains the same whether or not one accepts all of our criteria. If we do not insist on bivalence—binary measurement of only the presence or absence of a trait—these or other criteria are sufficient to distinguish between individual patients or patient conditions without denying the humanity of any single subject. The efficacy of group support systems in building a consensually acceptable model or hierarchy is reviewed elsewhere (Vennix, 1995).

1. *Physical Signature:*

1.a. *Genotype:* Humanness includes conformity to a species-specific genetic pattern dictating a set of innate mental and physical potentials which are typically realized over time, usually through social instruction (children) and interaction (adults). Humans are also genetically gifted, "hard-wired" in the current jargon, with an innate potential for learning both tool use and language (Rymer, 1992), the latter making possible (3.a.) communication, abstract thought, and demonstrable (4.a.) self-awareness.

1.b. *Physical form (gross):* The human form is defined by limbs allowing bipedal movement, arms with hands whose opposing fingers allow grasping and manipulation, external sensors (eyes, ears, etc.) and speech organs, and other characteristic morphological attributes.

1.c. *Appearance:* Departure from socially accepted standards of external appearance, irrespective of gross physical form, may result in social prejudice such that people feel "un-human." The history of adverse treatment on the basis of sexuality, skin color, or departure from social standards of appearance requires inclusion of this criterion. The psychological literature on children with obvious disabilities or visible deformities (King, Rosenbaum, Armstrong, and Miller, 1989; Rabiner and Coie, 1989; Rosenbaum and Armstrong, 1992; Levebvre and Arnd, 1988), for example, suggests early social exclusion of those who are different.

2. *Cognitive Signature:*

Approximately a third of Fletcher's criteria are directly or indirectly concerned with mental functioning and capability including: "neocortical function," "self-awareness," and "time sense." For convenience, these are combined into three attributes:

2.a. "Intelligence" here refers to higher brain functions of categorization, organization, storage, and integration of data. Several of Fletcher's criteria (for example, "time sense") are subsumed in this category. General intelligence quotient tests offer broad measures of high functions, some of which can be tested more narrowly by neurologists, psychologists, and psychiatrists.

2.b. "Perception" describes pre-integrative neurologic response to sensation and stimuli irrespective of mediating organization or categorization.

2.c. "Autonomic Functions" are primary reflexes, including respiration, sucking, grasping, and the like. The relation of autonomic "brain stem" functions to questions of patient "life," and thus patient humanity, has been well reviewed (Byrne and Nilges, 1993).

3. *Communal Signature:*

Almost 50 percent of Fletcher's list is partly or wholly concerned with the interpersonal and social characteristics of humanness.

3.a. Communicative potential: Whatever a person's social or interpersonal potential, it requires the ability to communicate before it can be realized. Thus a greater or lesser communicative ability is a prerequisite for other elements in this signature.

3.b-c. Social capacity: "A person exists not in isolation from others, but only through relationships. We are as we relate" (Silberstein, 1989). Thus individual potentials are activated only through social association, defined here, after Fletcher, as the capacity to (3.b.) relate to others and to (3.c.) care for others. A psychopath may have excellent relational skills, for example, but be unable to "care" for others or consider their needs.

3.d. Attachments: The ability to form sustaining relations with others is an essential human element. Failure of short-term memory or integrative function in patients with conditions like Korsokov's Syndrome or Alzheimer Disease, or resulting from trauma to the brain, may result in an inability to form or in some cases to maintain sustaining attachments.

3.e. Humans also are marked by what Lewis Thomas called a "drive to be useful," materially and socially, to their fellow species members (Thomas, 1992). The tool user must have something to build, and someone to create that object for. The language user requires an audience for his or her words.

4. *Individual Signature:*

Whatever their physical condition, intellectual ability, or social station, all humans have individual experiences, relations, and qualities. If they can be stored and processed (cognitive signature), then according to Fletcher's paradigm they will typically result in:

4.a Self-awareness, the end result of cognitive potential, social training and communicative capacity.

4.b. Self-control, which is similarly the result of social training and unimpaired cognitive functioning.

4.c. Creativity, which while not an element in Fletcher's paradigm, is so honored by society at large, as to warrant inclusion here.

4.d. Uniqueness: Each person's history reveals a series of decisions, of associations and accomplishments, which over time become a personalized signature. 3(b) allows for those choices to be recognized.

5. *Time.* Humans share a singular and complex time sense composed of memory (of prior events), hopes and plans (future events), and immediate realities (the present) (Sacks, 1995). Further, humans develop capacities and abilities over time, and may lose some or all of those capacities and abilities at any time as a result of illness or injury.

In structuring this hierarchy, a series of decisions had to be made about individual criteria. For example, we decided to use a person's past achievements, current performance, and future potential in society as level-one attributes. After all, if what is sought is a social determination of the human reality of a person, then the time frame must reflect the social context rather than an individual's cognitive frame alone. On the other hand, the ability of a person to perceive time, while emphasized by Fletcher, results from a complex interplay of both general intelligence, brain functioning and social interaction, criteria covered elsewhere in the set. Thus the act of creating the hierarchy, presented here as Figure 1, required a series of judgments on how and at what level specific criteria should be included.

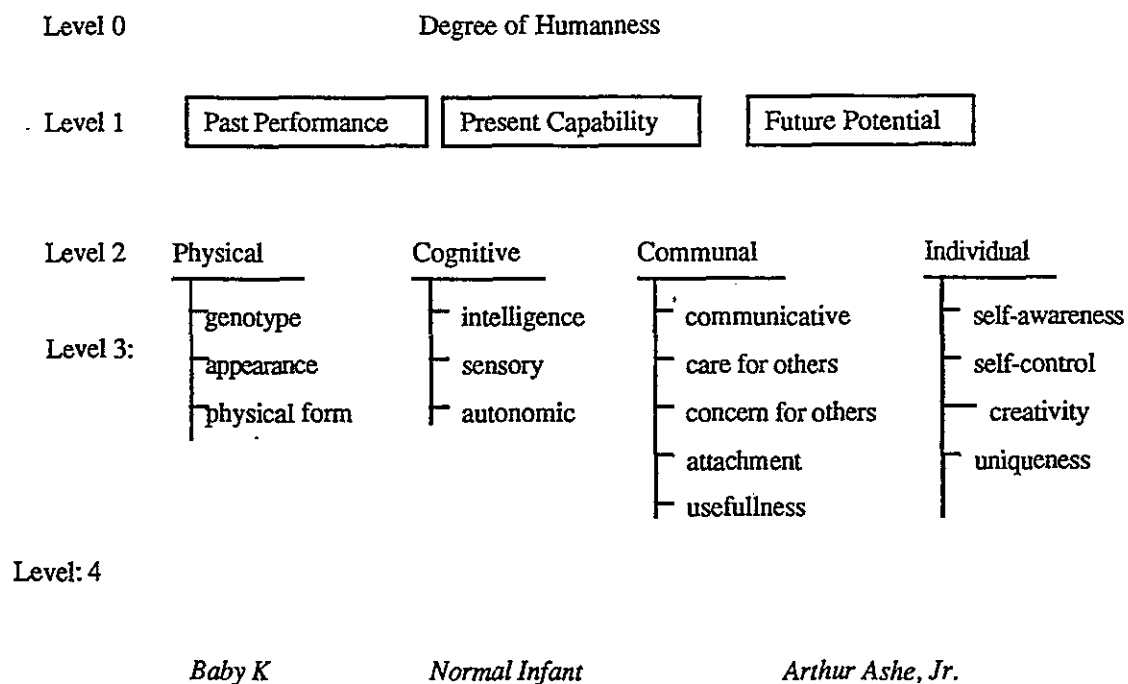
The model's social and interpersonal emphasis, while anticipated by Fletcher, also reflects a growing recognition of the degree to which, as a species, our development and abilities are defined through long-term association with others (Nelson, 1995; Wertsch, 1985). More important yet is the compensatory nature of the model. Although an individual may perform quite low on one or more attributes, the degree of humanness he or she exhibits may not necessarily be low, since higher scores on other criteria can offset, or compensate for, those deficiencies. Persons with Korsokov's syndrome, for example, are unable to perceive time because of a failure of short-term memory. Severely autistic children cannot communicate easily with others. No

one, however, would deny the humanity of either class of patient, or deny them treatment because of their failure to exhibit normal levels of those traits.

Application

Let us now illustrate how a multi-attribute assessment can use relative measurement to show differences in humanness between severely anencephalic infants and adult AIDS patients, the polls cited by Judge Hilton in the Baby K decision. We will use the AHP as the assessment procedure, employing verbal comparisons according to the conventional 1-to-9 intensity scale, and the hierarchy in Figure 1 as our interpretation and evaluation of Fletcher's criteria. At the bottom of the hierarchy, let us consider as alternatives a specific case each of anencephaly and AIDS, Baby K., and Arthur Ashe, Jr., respectively, as representatives of their classes. To facilitate interpretation of the assessment, let us also consider an average, healthy infant.

Figure 1



Within this hierarchy, both Baby K. and Arthur Ashe, Jr., the champion tennis player infected with AIDS through a blood transfusion, are generally representative of, on the one hand, a severely anencephalic infant, and on the other, an HIV+ adult. Both became examples, and perhaps public symbols, of their respective diseases: Baby K's fame came through the court case which bears her name (Sharni, 1993), Mr. Ashe's both through his writings (Ashe, 1993) and through media appearances in which he discussed the reality of living with AIDS. Further, we know a great deal about both examples. We know, from court and news records, about Baby K's physical condition and family situation, including the degree to which her mother's insistence on her daughter's survival resulted from strong religious convictions. Mr. Ashe's attributes and considerations are even better documented. A premier professional tennis player and a respected author, his personal characteristics (determination, modesty, intelligence), physical abilities, and tight familial bonds have been well described in both the tennis literature and the general media (McPhee, 1969).

In a hospital or community application of this process, the hierarchy would be analyzed and pair-wise comparisons conducted by a broad group of stake holders, including hospital personnel, patient advocate groups, and community members. For the purposes of this illustration, however, author judgments are utilized. In conducting the assessment, we first observe the irrelevance, in this problem, of genetic conformity and outward characteristics, and to some extent, the redundancy of traditionally measured IQ. All three individuals would share an apparently equal genetic conformity, and all three meet general standards of physical appearance and gross physical form. The anencephalic infant's skull typically exhibits a characteristic physical deformity, but none would argue that in and of itself a reason for rejection from the set of humans. As other

rankings demonstrate, IQ may represent a gross indicator of social, interpersonal and behavioral standards which are probably more relevant than basis points on the Stanford Binet scale. That inadequacies of definition are made overt in this application is not a trivial virtue.

While Baby K's genetic structure is recognizably and normally human (criterion 1.a.), and her general appearance that of any infant (1.c.), she had the characteristically deformed skull shape common to severely anencephalic children (1.b). Thus her physical appearance and genotype were those of a normal child, albeit one with a singular and apparent malformation. Because of the failure of her brain to develop, she lacked both the capacity for demonstrable "intelligence" and for typical sensory perceptions (auditory, visual, olfactory, etc.). She did retain residual autonomic functions (sucking and respiration) (2.c.), albeit at a level which required periodic assistance. Thus her case was occasioned by a need for occasional ventilator assistance. On the scale of humanness proposed here, she scored below average on autonomic functions and minimally for sensory perception (2.b.) and intelligence (2.a.). More seriously, her deficits mean she lacked both present and future capacity for communication and other aspects of the social signature (3.a-e). Finally, because of a lack of any but autonomic functions, her scores on the individual signature were also minimal.

By way of contrast, a normal infant of equal age would also present a normal genotype and a similar physical appearance, but without the anencephalic deformation of the skull. Thus it would score slightly higher than Baby K in its physical signature. While its demonstrable intelligence is clearly minimal at that age, a typical infant's autonomic functions are typically stronger, requiring no periodic ventilation. And while its cognitive abilities are usually "minimal," with perception, categorization and memory developing during its first months, "intelligence" based on their integrated use requires years of training to emerge. Similarly, an infant's individual and social signature is minimal, although expected to improve with maturation.

While neither infant will score strongly in the category of past activity and accomplishment, and their levels in a current time frame are somewhat distinct, their future potentials diverge markedly. One might say the normal infant is all hope and potential, qualities not assignable to the severely anencephalic infant. A normal infant therefore will score somewhat higher in some areas in the present, and in a future time frame their scores will be far higher than a severely anencephalic infant whose life expectancy is short and whose physical deficits preclude development across its life span.

Arthur Ashe, Jr., on the other hand, demonstrated an at least average genotype allowing for high levels of, on the one hand, intellectual achievement, and on the other, physical abilities requiring superior eye-hand coordination and agility. His intelligence and his ability to organize, categorize, and integrate data (2.a.) were widely admired by interviewers, who also saw in him a self-awareness and self-control (4.1-b) which seemed unusually well developed (McPhee, 1969). A devoted husband and parent, his social attachments to family and friends were similarly detailed by biographers and journalists who covered his life and career. Further, both his communicative skills and social capacity were superior, resulting in his authorship of books on tennis, the history of Black athletes, and a memoir describing, among other things, his life with AIDS (Ashe, 1988). Thus he scored higher in most areas, including uniqueness and interpersonal relationships. After being diagnosed as HIV+, Ashe's effective use of his public position to act as a champion and advocate for those unlucky enough to have been infected by the HIV virus exhibited a high level of social concern. That he took these public stands in the hopes his openness would benefit others makes clear a strong societal drive for usefulness. Clearly, his contributions to both his sport and society at large were unique.

In terms of level-one criteria, his record of past achievements was strong. And during the period of his illness, even when he did not play tennis, his advocacy and writing assured a very positive evaluation. Since his long-term prognosis was poor, however, his ranking in the future time frame was reduced. While some have lived longer than ten years following a HIV+ diagnosis, the typical period preceding AIDS terminal phase is far shorter, and thus his future time frame was restricted.

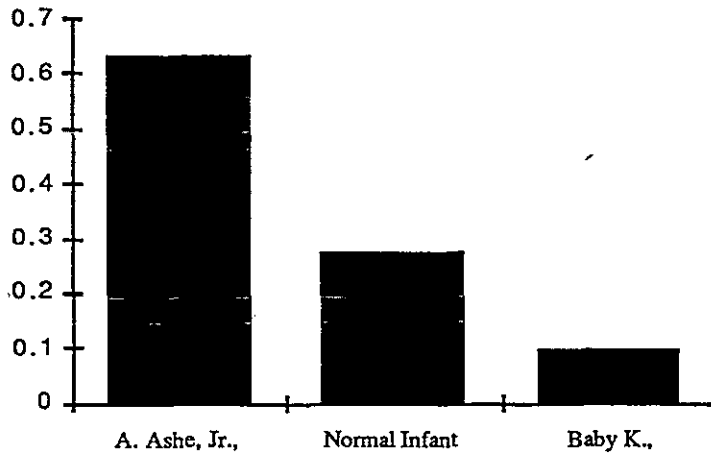
Discussion

The results of a pre-test applying the model to three test cases—Baby K, Arthur Ashe, Jr., and a normal infant, one facing neither a life-limiting nor threatening disease,—were gratifying. Synthesizing all criterion assessments for the entire hierarchy yielded, in an ideal mode: A. Ashe, Jr., 631; Normal Infant, .274; Baby K., .095. These results are presented graphically in Figure 2.

Thus the humanness of all subjects is asserted. There is no zero value. No class of non-living humans has been created. Still, differences of degree are recognized. The active and socially conscious adult receives a higher cumulative score than either infant. The normal infant who is expected to develop into at least an

average adult is accorded a higher judgment than the severely anencephalic infant on the basis of that expectation. These respective, overall judgments reflect the candidates' individual conditions in the context of the overall hierarchy.

Fig: 2 Overall results



In the pairwise comparisons of level-1 criteria, judgments emphasized the present condition (.656) over both past performance (.223) and possible future activities and growth (.121). The greater importance given to a candidate's present state over past accomplishment or future outcomes reflects a common medico-legal and social emphasis on "what is," on patient assessment, and secondarily the weight society at large gives to those of every age whose immediate and past contributions merit social recognition and support. Similarly, special consideration for those with marked past accomplishments, irrespective of possible outcomes, is one which has been argued elsewhere in both popular and bioethical literatures (Kolata, 1995).

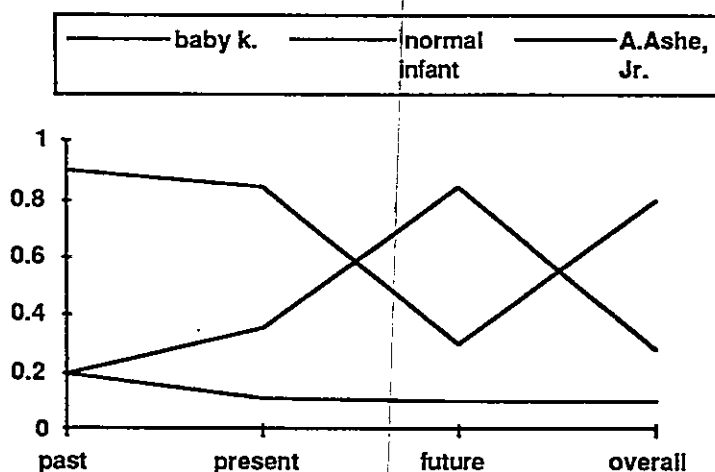
Level-2 judgments, summarized numerically, were: communal (.451) and individual (.315) criteria over those measuring cognition (.175) and physical (.058) condition. Emphasis on the communal criteria over one emphasizing the individual also favors the mature adult over the infants because that person has had time to develop social and communal responsibilities and relationships. Similarly, the probability that the normal infant in maturity will be a social and communal person explains that child's score in relation to that of the anencephalic infant.

The hierarchy clearly favors the HIV+ candidate, Arthur Ashe, Jr.—a parent, scholar, spouse, and public figure—over the infants in this comparison. The normally maturing infant will score slightly higher in the present, and far higher in a future time frame, than the infant with Down Syndrome. The latter can not, after all, develop individual or communal abilities without requisite brain function. Obviously, to the extent we can predict a successful maturation, the normal infant's performance with respect to these criteria will improve while that of the anencephalic infant would, if it lived, remain constant. But since neither Baby K or Arthur Ashe, Jr., had long life expectancies, to the extent a future time frame is emphasized, the rank order between the control infant and Ashe will be reversed.

This complex of judgments is summarized in Illustration 1, which depicts candidate comparison across the three level-1 time frames. This "sensitivity performance" graph, generated by Expert Choice software, aggregates judgments from the goal node across the criteria. It thus represents a synthetic summary whose comparative judgments separately sum to one (see above), but whose combined, graphic representation does not. If the sole context were one of future life expectancy, the normal infant's probability of a longer life span would give the highest ranking. But because we do accord weight to past accomplishment and current activities, the adult with AIDS is shown to have the higher overall rating.

There is, in short, a demonstrable and definable difference of degree differences among an infant without the sensory or cognitive apparatus ever to be a self-aware or active member of society, another with that potential, and a person who has demonstrated high levels of performance at every level. Further this difference can be discussed in terms of specific criteria and their application.

Illustration 1: Summary: Sensitivity Performance Graph



Here we see the importance of insisting on the stated hierarchy as one detailing not “personhood” but “humanhood.” In light of this hierarchy, one might say that Baby K’s deficits denied it more than minimal personhood, that its participation in this set is limited by low scores in cognitive, interpersonal, and individually unique criterion categories. Its humanity however is not challenged or questioned because its score is higher than “zero”. To the extent this reflects a concern with not merely “humanness” but with “personhood” as a social and interpersonal quality, one allowed by self-awareness and communicative abilities, the anencephalic child sits at the periphery of the protective circle justice creates.

Put another way, our approach suggests that an individual with AIDS—or any similar illness with the potential of future limitation—may be more a person but not necessarily less human than a severely anencephalic child. This is true not simply because of the adult’s social and individual history—something all infants lack—but because the reality of and potential for individual activity, interpersonal development, and social interaction is more limited for the one than for the other. This approach permits us to describe the difference between an anencephalic infant, a normal infant, and an HIV+ person in a way which does not deny the humanity of any individual. Nor does it create a class of “non-persons” or non-humans. It describes instead a field of observed differences between claimants on the basis of, first, past, present and future frames, and secondly, on the basis of cognitive, interpersonal, perceptual, and communicative abilities. In short, it both answers the challenge of the Baby K decision and does so in a way which vouchsafes the humanity of fragile claimants irrespective of their probability of survival.

Conclusion

Attempts to find a generally accepted solution to the questions raised by maintenance of severely anencephalic children have failed to find consensus. The question has been whether infants are or are not human individuals under the law, equal to all others, and thus eligible for its protection. Medically, this question has been examined as a function of whether the severely anencephalic infant with residual brain-stem function should be considered “alive” or, alternatively, “clinically” dead but breathing with mechanical assistance. The issue of care of anencephalic infants represents a class of bioethical problems involving issues similar to those patients said to be in a “permanent vegetative state”.

When framed as a bivalent problem, no answer is possible because the line between living and dead, person and non-person, is necessarily a fluid social definition variously constructed by different parties. However, when the question is phrased using a compensatory, multicriterion approach (e.g. AHP)—methodologies which allow discussion of degrees of an element’s membership in a set—distinctions emerge which build upon both clinical observation and social definition. There is indeed a describable, quantifiable difference between an HIV+ person and a severely anencephalic infant. It is, however, a matter of degree and not of kind.

Obviously, further work will be required before such a hierarchy can be applied, either in a single institution or as a social standard. This approach demonstrates the problematic issues of species self-determination, and

an applicable hierarchy surely will be a matter of serious debate among stake holders. We have included judgments for illustrative purposes, but to be useful this or another hierarchy will need to be presented to and discussed by a representative range of constituents interested in the issues. These will include in a partial list: members of legal, medical, and perhaps pastoral communities, legislators, and stake holders from the broader community, as well as patient representatives.

Some might argue that comparing a person like Arthur Ashe, Jr., with a severely anencephalic infant is unfair. Obviously, the former will win. But the point in law has been that they are equal. This was the heart of the landmark decisions regarding anencephalic organ donation, especially In the Matter of Baby K. The advantage the approach we advocate is that it permits us to recognize and measure gradations obscured by traditional, bivalent approaches. These gradations define various middle grounds absent in an Aristotelian world of opposites, a world ruled by the law of the excluded middle (Kosko, 1993). The translation of the debate into this framework offers, perhaps, a potential for consensus. At the very least it permits a critical evaluation of the bivalent arguments which so far have proved arbitrary, dogmatic, and, ultimately, futile.

We believe that as long as problems like those presented by the issue of anencephaly are framed bivalently that no generally satisfactory answer is possible. The line between living and dead, person and non-person, is necessarily a fluid social definition variously constructed by different parties. When the question is phrased using a compensatory, multivalent approach (e.g., AHP)—a methodology allowing discussion of degrees of an element's membership in a set—however, distinctions emerge which build upon both clinical observation and social definition. There is indeed a describable, quantifiable difference between an HIV+ person requiring ear surgery and a severely anencephalic infant. requiring ventilation treatment It is, however, a matter of degree and not of kind.

References

- AMA Issues statement on anencephalics as Living Donors. *J. Law, Medicine & Ethics* 1995; 23:3, 206-7.
- American Medical Association Council on Ethical and Judicial Affairs. The use of anencephalic neonates as organ donors. *J American Medical Association* 1995; 273:20, 1614-1618.
- Ashe, A. Jr. *Days of Grace: A Memoir*. NY: Knopf, 1993.
- Ashe, A. Jr. *A History of the Afro-American Athlete: 1619-1918*. NY: Warner Books 1988.
- Atkin, RH. *Mathematical Structure in Human Affairs*. NY: Heinemann, 1974.
- Brock, DW. Voluntary Active Euthanasia. in, *Dying Well? A Colloquy on Euthanasia & Assisted Suicide* Hastings Center Report 1992; 22:2, 11.
- Byrne, PA. and Nilges, RG. The Brain Stem in Brain Death: A Critical Review. *Issues in Law and Medicine* 9:1,1993); 9:1, 3021.
- Byrne, PA. Evers, JC. and Nilges, RG. Anencephaly—Organ Transplantation? *Issues in Law and Medicine* 1993; 9:1, 23-33.
- Dennett, D. Conditions of Personhood. in Oksenberg, AR. *The Identities of Persons*. Berkeley: U. California Press, 1975, 175.
- Fletcher, J. *Humanhood: Essays in Biomedical Ethics*. Buffalo: Prometheus Books, 1979. 7-19.
- Gerhart, KA, Koziol-McLain, J. Lowenstein, SR and Whiteneck, GG. Quality of Life Following Spinal Cord Injury: Knowledge and Attitudes of Emergency Care Providers. *Annals of Emergency Medicine* 1994; 23:4, 807-812.
- Glover, JJ., Rushton, CH. Introduction: From Baby Doe to Baby K: Evolving challenges in pediatric ethics *J. Law, Medicine & Ethics* 1995; 23:1, 5-27.
- Goldberg, AB. "In the matter of Baby K." Letters to the Editor. *J. Law, Medicine & Ethics* 1995; 23:3, 300.
- Gould, P. The Tyranny of Taxonomy. *The Sciences* May/June, 1982, 7-9.
- In re T. A. C. P. 609 So 2nd (Florida) 1992, 588, 589.
- In the Matter of Baby K. United States District Court. 832 F. Supp. 1022. Civ. A. No. 93-68-A. July 1993, 1027.
- King, SM., Rosenbaum, P., Armstrong, R. and Milner, R. An epidemiological study of children's attitudes toward disability." *Developmental Medicine and Child Neurology* 1989; 31, 237-245.
- Kittay, EF. and Meyers, DT. The Justice position and the care perspective, in Kittay and Meyers, ed. *Women and Moral Theory* Savage, Maryland: Rowman and Littlefield Publishers, Inc. 1987, 4-10.
- Koch, T. Normative and prescriptive criteria: The efficacy of organ transplantation allocation protocols. *Journal of Theoretical Medicine* 1996; 17:1, 75-93.
- Kolata, G. Transplants, morality, and Mickey. *New York Times*, June 11, 1995, Sect. 4, 5.
- Kosko, B. *Fuzzy Thinking*. NY: Hyperion, 1993.

- Levebvre, A. and Arndt, E. Working with facially disfigured children: A challenge in prevention. *Can. J. Psychiatry* 1988; 33, 453-458.
- McPhee, J. *The Rules of the Game*. McFarlane Walter and Ross: Toronto, Canada, 1969.
- Merola, MJ. Fourth Circuit holds that hospital must provide care for anencephalic baby. *J. Law, Medicine & Ethics* 1994; 22:2, 183.
- Nelson, HL. Dethroning choice: Analogy, personhood, and the new reproductive technologies. *J. of Law, Medicine & Ethics* 1995; 23:2, 133-134.
- Rabiner, D. and Coie, J. Effect of expectancy inductions on rejected children's acceptance by unfamiliar peers. *Developmental Psychology* 25:1989, 450-457.
- Rosenbaum, PL. and Armstrong, RW. Self Perceived social function among disabled children in regular classrooms." *Developmental and Behavioral Pediatrics* 1992; 13:1, 11-16.
- Rymer, R. A Silent Childhood II. *New Yorker*, April 20, 1992, 67-69.
- Sacks, O. *An Anthropologist on Mars*. NY: Knopf, 1995, Ch. 2, 4.
- Sharni, L. Organ donation can become ethics issue." *USA Today* October 13, 1993.
- Sobsey, R. Compassionate homicide versus equal protection: *Archives of Physical Medicine and Rehabilitation* 1992, 934-939;
- Spielman, B. Collective Decisions About Medical Futility. *J. Law, Medicine & Ethics* 1995; 22:2, 152-160.
- Silberstein, LJ. *Martin Buber's Social and Religious Thought*. NY: NY University Press, 1989, 128.
- Spike, J. and Greenlaw, J. Persistent brain death and religion: Must a person believe in death to die? *J. Law, Medicine & Ethics* 1995; 23:3, 291-2984.
- Sytsma, SE. Anencephalics as Organ Sources. *Theoretical Medicine* 1996; 17:1, 19-32.
- Thomas, L. *The Fragile Species*. NY: Collier Books, 1992, 26.
- Vennix, J Building consensus in strategic decision making: System dynamics as a group support system. *Group Decision and Negotiation* 1995; 4:4, 336.
- Weiss, D. Baby K and the courts' reading of EMTALA. *J. Law, Medicine & Ethics* 1994; 22:4, 358-9.
- Wertsch, JV. *Vygotsky and the Social Formation of Mind*. Cambridge: Harvard University Press, 1985.
- Young, J, Marshall, CL, and Anderson, EJ. Amyotrophic Lateral Sclerosis patients' perspectives on use of mechanical ventilation. *Health and Social Work* 1994; 19:4, 253-260.