

RELIGIOUS REASONING IN HEALTH CARE RESOURCE MANAGEMENT: THE CASE OF BABY K†

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How should society respond to persons who claim—on religious grounds alone—that they are entitled to health care resources that health care providers believe confer only marginal benefit, if any at all? The frequency of such religious accommodation is murky; until recently it has seldom been publicly commented on. The more notable recent examples include indigenous Americans who demand that a brain-dead suicide victim be maintained on life-support until the spirit has vacated the body, Orthodox Jews who demand that brain dead relatives be supported by a respirator in an intensive care unit (ICU) for more than ten days,¹ parents who ask for male circumcision of their infants, and Africans who request female genital mutilation. These are a few examples of those who request health resources that some health professionals argue provide little or no benefit. These cases would be of little social consequence, except that the religious reasons that underlie these requests press at a larger social question of what role religious accommodation should play in a liberal democracy. If hospitals—or, with growing frequency, managed care organizations—are generally inclined to deny such requests for treatments that are of little or no benefit, should they make exceptions and accommodate the religious beliefs of consumers? This paper explores what is, and ought to be, the relation-

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¹ See NEW JERSEY COMMISSION ON LEGAL AND ETHICAL PROBLEMS IN THE DELIVERY OF HEALTH CARE, *THE NEW JERSEY ADVANCE DIRECTIVES FOR HEALTH CARE AND DECLARATION OF DEATH ACTS: STATUTES, COMMENTARIES AND ANALYSES*, at 88-89 (1991) (discussing § 5 of the New Jersey Declaration of Death Act that requires a physician to continue cardio-respiratory support for a patient who could be declared dead based on neurological criteria, but where such a declaration of death would violate the patient's religious beliefs). The comment to § 5 states that cardio-respiratory support should continue "until it is determined, in accordance with currently accepted medical standards, that irreversible cessation of all circulatory and respiratory functions has occurred." *Id.* at 89. Section 5 of the New Jersey Declaration of Death Act is codified at N.J. STAT. ANN. § 26:6A-5 (West Supp. 1994).

ship between religious reasoning and resource management for health care services, and in particular, the management of services that some claim are futile—with little or no medical benefit.

Limiting health care resource utilization is difficult enough a task because courts, legislatures, and other policy makers maximize private discretion and choice and minimize private decision making to meet the needs of the greater public. It is nearly impossible to limit health resource utilization because choices are made at the individual level, as private preferences of individual patients, with little attention paid to the larger social need. Complicating matters, the issue of resource management becomes more strained when, in private decision making, one is able to choose "ineffective" treatment for oneself, one's child, or one's incapacitated relative.² The resource management issue reaches a distinctive protracted conflict when, as in the case of Baby K,³ the issue is couched in religious terms. Society might tolerate private decision making for health resources even when the treatment is thought to confer little or no benefit to the patient. When the request for health resources that confer little or no benefit is based on religious claims, however, some health care providers hesitate to comply on the ground that such claims have less standing in a liberal democracy. Oddly, providing no reason (i.e., remaining silent) is better than some reason (i.e., religious reason).

In the growing public debate about denying futile care, the case of Baby K stands out in part because the testimony of the mother, Mrs. H, appealed to religious ideas. Mrs. H demanded that Fairfax Hospital in Virginia keep her anencephalic daughter, Baby K, on a respirator. The trial court recorded the following facts:

She (Mrs. H) believes that all life has value, including her anencephalic daughter's life. Mrs. H has a firm Christian faith that all life should be protected. She believes that God will work a miracle if that is His will. Otherwise, Mrs. H believes, God, and not humans, should decide the moment of her daughter's death. As Baby K's mother and the only parent who has participated in the infant's care, Mrs. H believes that she has the right to decide what is in her child's best interests.⁴

For some, Mrs. H's decision on behalf of Baby K falls beyond

² Rebecca Dresser, *The Public Context of Private Decision Making*, HASTINGS CENTER REP., May-June 1994, at 21-22.

³ *In re Baby K*, 832 F. Supp. 1022 (E.D. Va. 1993), *aff'd*, 16 F.3d 590 (4th Cir.), *cert. denied*, 115 S. Ct. 91 (1994).

⁴ *Id.*

the pale, beyond the bounds of acceptability, simply because her reasoning is religious; religious-based requests are so unreasonable that society can deny them. Admittedly, this is an extreme sentiment held by very few and voiced by even fewer, but at its base this sentiment is one that has animated public debate since our republic's founding. It is the question of what role, if any, religious reasoning should play in a liberal democracy. This paper has no pretensions to answer fully this question; others have begun that task with success.⁵ Rather, this paper will address a smaller aspect of the large question: What weight, if any, should be given to religious arguments that are used to procure health resources, which some believe are futile? More specifically, should religious reasons be accommodated in futility cases if other nonreligious reasons for the same futile services would fail, and if so, under what circumstances? This paper disaggregates the issues posed by these questions and suggests that in the present state of resource management, it is generally indefensible to override choices that are based on religious reasoning. In a more coherent and fairer form of resource management, it is defensible not to accommodate some religious requests for health resources.

Specifically, this paper will defend four theses. First, in the present form of resource management, religious reasons should be treated no differently from any other class of reasons for allocating resources. Since restricting medical resources is a contested area, religious reasons are as legitimate as any others to secure resources. Second, even though there is a general presumption in favor of the acceptability of religious reasons, there are cases such as harm to the child where the religious reasons can be overridden. Third, religious reasoning can be overridden in a just system for the allocation of health services, one in which the system of allocating is explicit and public, the criteria for allocation reflect society's values, and the process and appeals system are considered fair. Fourth, whether resources are managed as they are currently, or in a more ideal situation, the task of resource management can gain insights from religious reasoning that might otherwise be lost.

Before proceeding to these theses, clarification of some terms and boundaries of the argument is in order. First, religious reasoning refers to a broad class of claims that are knowable exclusively, or in part, from revelation and not knowable in the first instance from common human reason—reasons that often go uncontested. The fact that religious reasons arise from revelation does not to

⁵ KENT GREENAWALT, *RELIGIOUS CONVICTIONS AND POLITICAL CHOICE* 3-49 (1988).

imply they are necessarily inconsistent with common human reasons, which are rarely dismissed as a class. This paper is concerned with religious reasons as a class. Because of this focus, the truth or falsity of religious claims from various theological perspectives—Jewish, Christian, Muslim, Hindu, Buddhist—is unimportant.

In the case of Baby K, the truth or falsity of Mrs. H's claims is also unimportant, either from her own religious vantage point or from any other philosophical perspective. The case of Baby K is not fully representative of all religious reasons about resource management; few commentators, if any, say much about this topic. Nonetheless, Mrs. H's religious reasons have been contested both within religious communities and in the larger public debate. For example, her claim that "all life has value" is represented by significant religious and secular versions of the same argument.⁶ One interpretation of this dictum is that life should be protected by all means. This interpretation has been criticized as being vitalist because the obligation to sustain life is not an absolute requirement, to be protected in every instance. Regardless of the merits of any individual religious reason for resource management, this paper is concerned with the questions: what part do, and should, the class of religious reasons play in resource management, and for that matter in a liberal democracy?

Second, health care resource management is a system's ability to determine what health services will and will not be offered. A variety of institutional mechanisms exist to accomplish this goal, including futility policies, admission and retention criteria for intensive care units, drug formulary decisions, and any processes or structures—formal or informal—that limit or totally deny health care resources. Institutional mechanisms that manage resources rely not only on criteria such as futility—the service does not work or provides little benefit—but also on criteria such as "medical necessity" or "proven worth." This paper focuses only on futile and ineffective care, and its broad point does not rise or fall on whether the concept of futility is a defensible one.⁷

Third, in the broad health care context, within which the accommodation and futility debate transpires, a decisive shift is occurring in sentiment and policy. A broad agreement exists that there is no coherent public policy for health care resource man-

⁶ PAUL RAMSEY, *THE PATIENT AS PERSON* xi (1970).

⁷ See James Lindemann Nelson, *Families and Futility*, 42 J. AM. GERIATRICS SOC'Y 879 (1994); Robert Veatch, *Why Physicians Cannot Determine if Care is Futile*, 42 J. AM. GERIATRICS SOC'Y 871 (1994).

agement at the moment, except a public policy through default. Some describe this default policy as a "rule of rescue," namely, the willingness to expend resources by saving one identifiable individual life, no matter how high the cost, no matter how little the medical benefit.⁸ Therefore, until recently, futile care has been regularly administered regardless of the reasons, but the current futility debate is one attempt to bring some coherence to a system in disarray.

Fourth, a legal presumption exists that parents can exercise discretion about how they rear their children.⁹ Parents traditionally have been considered to have the primary right, a "natural right to control their children's nurture."¹⁰ The First Amendment protects the rights of citizens to raise their families in privacy, and also allows them to practice the religion of their choice. In large measure, courts have been willing to allow parents to raise their children as the parents see fit, unless there is some compelling state interest that is framed in terms of "quality of a child's life" or the "right to a normal life."¹¹ Parent's religious claims have generally been honored except in cases of forgoing life-sustaining treatment. This restriction was based on the now famous legal axiom: you can martyr yourself, but you cannot martyr your child.¹² Yet the applicability of this axiom is questionable in the Baby K case because the axiom refers most clearly to the removal or withholding of treatment, and far less clearly to cases where treatment is provided.

THESIS 1

In the present state of affairs of health care resources management, religious reasons as a class are generally no more unjustifiable than any other (nonreligious) idiosyncratic reasons for managing resources, even when applied to resources that are deemed to be medically futile. Few health care professionals refuse to give health resources simply on the basis that it is a religious

⁸ See Philip J. Boyle & Daniel Callahan, *Minds and Hearts: Priorities in Mental Health Services*, HASTINGS CENTER REP., Special Supplement Sept.-Oct. 1993, at S3, S7; David C. Hadorn, *Setting Health Care Priorities in Oregon: Cost-Effectiveness Meets the Rule of Rescue*, 265 JAMA 2218 (1991).

⁹ 1 WILLIAM BLACKSTONE, COMMENTARIES 194 (Bernard C. Gavit ed., 1941).

¹⁰ Jane E. Probst, *The Conflict Between Child's Medical Needs and Parent's Religious Beliefs*, 4 AM. J. FAM. L. 175; Stuart J. Baskin, Note, *State Intrusion into Family Affairs: Justifications and Limitations*, 26 STAN. L. REV. 1383, 1384 (1974).

¹¹ See, e.g., *Prince v. Massachusetts*, 321 U.S. 158, 166 (1944); *Meyer v. Nebraska*, 262 U.S. 390, 399 (1923); *Kilgrou v. Kilgrou*, 107 So. 2d 885, 888 (Ala. 1959).

¹² *Prince*, 321 U.S. at 170.

request. No one, for example, has explicitly claimed in the Baby K case that the mother did not have legal standing because her reasons were religious. On the contrary, in *Baby K*, the district court recognized and protected Mrs. H's ability to make decisions based on her religious reasons.¹³ For legal reasons, it is unlikely that these or other religious arguments will ever be straightforwardly rebutted. It is tactically easier to rebut Mrs. H's claims on medical and scientific grounds than to address religious reasons in court.

Regardless of whether religious ideals are ever confronted, it is not wild conjecture to believe that such ideals are so unreasonable that society excludes them from the choices that patients or their surrogates may make. As a society we remain ambivalent about what role religious reasoning should play in public decisions, especially when decisions of private citizens have some impact on state interests. Why? Religious reasons are thought to be irrational or just incomprehensible by many. Kent Greenawalt said it succinctly: "A good many professors and other intellectuals display a hostility or skeptical indifference to religion that amounts to a thinly disguised contempt for belief in any reality beyond that discoverable by scientific inquiry and ordinary human experience."¹⁴ Within medical decision making there is long-standing suspicion, indeed intolerance, of religious argumentation that challenges the medical norm. Such challenges are evidenced in now classic cases of Jehovah's Witnesses and other religionists refusing some treatment in favor of alternatives such as faith healing.

At a minimum, a position not to accommodate some religious reasons is self-defeating. History demonstrates that it is impossible for members of society to divorce themselves from patterns of reasoning devoid of religious beliefs. Whether or not we personally are religious, we live in a society that has transmitted religious values and reasoning that we either consciously or unconsciously adopt and adapt. It makes little sense to say that it is unacceptable to use religious reasons when many of the reasons we use are deeply imbued with religious origins and motivation. Today's non-religious personal premises are often yesterday's religious convictions. Concepts such as sanctity and dignity of the human person that arose out of religious dialogue are commonly used in the secular conversation. It makes little sense to claim that religious rea-

¹³ *In re Baby K*, 832 F. Supp. 1022, 1030 (E.D. Va. 1993), *aff'd*, 16 F.3d 590 (4th Cir.), *cert. denied*, 115 S. Ct. 91 (1994).

¹⁴ GREENAWALT, *supra* note 5, at 6.

sons are indefensible as a class because few reasons would ever escape the pervasive infiltration of religion.

Debunking another false dichotomy adds credence to a position in favor of religious accommodation. A portion of the futility debate turns on a questionable dichotomy that medical judgments about futility are more compelling because they are scientific and objective, whereas religious reasons are subjective and value-laden. The assumption is that medical judgments are objective, value-free, and preferred over religious, value-laden reasons. However, there is wide consensus that futility judgments are, and are likely to remain, far from being objective and value-free because there are so many interpretations of concepts imbued with values. If futility judgments are value-laden, it seems arbitrary in the present state of resource management to single out religious reasons, as opposed to any nonreligious and perhaps idiosyncratic reasons, as a basis to deny a resource.

THESIS 2

In the present state of resource management, it is defensible not to indulge in some religious reasons for the use of health resources that are thought to be ineffective or harmful, especially if reasonable alternatives exist. Female circumcision, sometimes morally weighted and termed "female genital mutilation," serves as the strongest case of not accommodating religious requests for health resources.¹⁵ Without investigating the internal religious logic of this practice—for example, it may not be a religious practice but a cultural one—many nonetheless argue that these practices are so unreasonable that society must exclude them from the choices that patients or their surrogates may make. The prohibition of female circumcision is justified simply because it gravely harms the child and provides no medical benefit. Less clear is the religious practice of male circumcision, which in the past was believed to confer medical benefit on men, including the decreased incidence of sexually transmitted diseases, certain types of cancer, and the rate of neonatal urinary tract infection. Yet an ongoing debate suggests that providing circumcision serves a questionable beneficial purpose because of complication rates, human suffering,

¹⁵ See Barbara Frye, *Ritualized Genital Mutilation: The Procedure*, UPDATE, Sept. 1994, at 1-7; Stephen A. James, *Reconciling International Human Rights and Cultural Relativism: The Case of Female Circumcision*, 8 BIOETHICS 1 (1994).

and economic costs.¹⁶ Consequently, managed care organizations are considering whether male circumcision should be covered because it is a procedure that serves no beneficial purpose and is requested, in part, for religious reasons. The denial of religious based requests is stronger when alternatives exist. For example, a child could choose when he becomes an adult whether to endure the procedure which will provide little, if any, benefit and may cause harm.

This harm thesis, however, does not fit the facts of the Baby K case. It is easy to imagine how some might conclude that Baby K was harmed by being placed on a respirator with no hope of living a normal life or experiencing her surroundings. Equally plausible, is Mrs. H's belief that it would have been abuse if every possible health resource was not given to keep Baby K alive. It is likely that Mrs. H thought that the respirator was a sign of respect consistent with her religious beliefs. Thus, whether Baby K was abused is contestable. When no consensus exists, it is questionable whether one should prefer any judgment other than the one of the mother who has been the sole provider for the child.

THESIS 3

With a more adequate, fair, and defensible account of resource management, limits can be placed on religious claims—indeed, on any claims for scarce resources. In addition to present day restrictions of religious accommodations (i.e., harm), it is possible under specific circumstances to limit religious accommodation. In the current management of resources in the United States there is no coherent public policy for the distribution of health resources because society remains uncertain about how to justly distribute the plentiful, but questionably limitless, health services. Society is uncertain whether a scarcity of resources exists and whether such scarcity is a moral prerequisite to limit services. Likewise, society is dubious in believing that the health resources saved by limiting them in one category will be put toward another category. For example, futile care as a moral prerequisite to justify limiting resources ensures that the resources are applied to the category that was intended. But a fairer system of management would go beyond assuring: (1) that there is scarcity, and (2) that money saved in one place will actually affect the goals society is trying to accomplish with the savings.

¹⁶ Michael S. Wilkes & Steve Blum, *Current Trends in Routine Newborn Male Circumcision in New York State*, 90 N.Y. ST. J. MED. 243, 243 (1990).

For resource management to be more fair, adequate, and defensible, the following would be required. First, the process for making decisions about managing resources must be more public, which currently it is not. Those people most affected by resource management decisions often have no say in the decision making process. Second, the criteria that are used to manage resources, not only are out of sight from the public, but also are deeply value-laden. Resource management criteria are deeply value-laden and should be left to experts, who have no claim to expertise about what the rest of society values. Instead, the criteria for resource management must reflect society's values.¹⁷ Third the process and appeals system for managing resources must be perceived as fair.¹⁸ If these three prerequisites are taken into account, they serve as a basis for placing limits on religious accommodation.

Attempts at resource management walk an ambiguous line between religious accommodation and establishment of religion. Ambiguity is likely to remain in the majority of cases. If, on the one hand, resource management proceeds toward accommodating every religious request for resources, while simultaneously society agrees that there are legitimate limits, it is likely that this direction will be perceived as the establishment of religion. If, on the other hand, resource management proceeds toward no accommodation of religious reasons, this direction will likely be contested as not providing reasonable accommodation and barring religion altogether. It will be difficult to balance these tensions; however, the balance will most likely be struck by favoring costless accommodations, and in the case of more costly accommodations, asking those who request a health service to pay a higher premium or to trade off benefits to which they are entitled. Whichever direction resource management takes, it must keep clearly in mind that religious reasons are a class that will be at times difficult to extricate from nonreligious reasons. Society will unlikely resolve its need to limit resources by shifting the locus of the debate to religion, because religious reasons as a class are inextricably bound with non-religious reasons.

THESIS 4

Under either the present circumstances or some more morally preferable and more defensible distribution of health resources,

¹⁷ Boyle & Callahan, *supra* note 8, at S18-19.

¹⁸ See generally CHARLES R. BEITZ, *POLITICAL EQUALITY: AN ESSAY IN DEMOCRATIC THEORY* (1989).

religious ideals contribute to the discussion of how to think about resource management. Religious reasons broaden the often narrow conceptions of how to manage resources. For example, close inspection of how resources are distributed disclose that often one or only a few narrow measures get used, usually some variant of cost-effectiveness, or cost-benefit ratio.¹⁹ One variant for managing resources is the best outcome.²⁰ With limited resources, patients are selected who will benefit most, while those who will benefit least are denied treatment. The person who is denied even a small benefit is likely to complain that she has been discriminated against. Why should she be denied even a small benefit simply because the criteria favor greater benefit? Such criteria point out which life is more valuable, namely, those that will benefit more from the resource. As I have argued elsewhere,²¹ these narrow conceptions possess an even narrower sense of who will be treated. At times these health measures—the criteria used to manage resources—discriminate against classes of people.

Religious reasons can productively add to these criteria by highlighting an expanded view of whose interests are taken into account and protected and what goals are served. Religious reasons can contribute to the discussion by expanding on and calling attention to values that might get overlooked in the secular and technical discussion. A good example of how religion broadens resource management is the theological anthropology found in many patterns of religious reasons. Some have implied that one reason that Baby K should not be given health resources is because she is almost less than human and thus does not deserve equal care and protection.²² A theological anthropology would force the public discussion as to whom it counts as human. For example, many Christian churches maintain that all life is sacred, no matter how impaired. Another example of how religious reasoning broadens resource utilization is through the revelation in Judaism and Christianity that society has an obligation especially to the *anawim*, that is, the poorest of the poor and the worst off. In a narrow, secular conception of resource management, it is plausible to distribute

¹⁹ Dan Brock, *Some Unresolved Issues in the Priority Setting of Mental Health Services*, in *WHAT PRICE MENTAL HEALTH? THE ETHICS AND POLITICS OF SETTING PRIORITIES* 276, 299 (Philip Boyle & Dan Callahan eds., forthcoming 1995).

²⁰ See I FRANCES M. KAMM, *MORALITY, MORTALITY: DEATH AND WHOM TO SAVE FROM IT* 263-64, 265-88 (1993).

²¹ Boyle & Callahan, *supra* note 8.

²² Robert M. Veatch, *The Impending Collapse of the Whole-Brain Definition of Death*, 23 *HASTINGS CENTER REP.*, July-Aug. 1993, at 18-24.

resources, not to those who are worse off, but to some who might be better off. Religious reasoning calls society to attend to those values that get left off the map—so to speak.

CONCLUSION

As a practical matter, the issue of resource management ought to be seen on a continuum. If there existed a broad consensus about the circumstances under which services are justifiably denied, conceivably the denials could be placed on a continuum reflecting whether the health service for this patient is futile, marginally effective, or of proven benefit. The continuum could be further complicated in cases where there is little proof whether the service is futile, marginally beneficial, or effective. As long as societal agreement exists on where the limits are to be drawn for health resource allocation, the private preferences of citizens can be overridden, regardless of the basis of their opinions, whether these opinions are religious or nonreligious. Society and the courts will be forced to balance how much religious accommodation there should be in this area, if any at all. However, when little consensus exists over the process of resource management and what counts as futile, then these contentious decisions ought to be left to those who are most intimately affected by the decision.

As a public policy matter, resource decision making ought to take into account the values that are a cherished part of one's religion, for example, that all life is sacred. To insure that limits are politically feasible, policy makers must take religious reasons into account. When a resource decision is being made, the decision makers must be careful to ensure that, despite whatever else is being said, the refusal does not imply that some lives are unimportant. In moral theory it is possible to simultaneously respect life and deny some forms of care that lead to the death of some persons.²³ It would be politically unwise to craft policy that defiantly diminished religious reasons as a basis for decision making.

²³ Joseph Boyle, *Who is Entitled to Double Effect?*, 16 J. MED. & PHIL. 475, 478-79 (1991).