

Ethics and Intellectual Disability

Hyperammonemia: Are the Burdens Too Grave? Case Study

Mendel Tuchman

A baby is born to a young couple who expect a healthy infant based on all the prenatal and perinatal indications. Within 24-48 hours after birth the baby refused to eat, became lethargic, and rapidly lapsed into coma at which time hyperammonemia is diagnosed. (This genetic disorder manifests only after the baby is born and the umbilical cord disconnected; the mother's liver detoxifies the ammonia of the baby through the placenta.) The baby needs to go on life support, as hyperammonemia causes brain swelling and, unless rapid therapy is instituted, the baby will die within a few days. The only life-saving procedure is hemodialysis to bring the ammonia levels down rapidly.

Most babies who are treated with effective hemodialysis will survive, but there could be complications such as stroke, obstruction of large vessels, infections. Once the ammonia has been brought under control, the baby will be treated with severe protein restriction and ammonia scavenging drugs and will be stable for about

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Intellectual Disability, Genetics, and Ethics: A Review

Susan Poland

The *Journal of Intellectual Disability Research* published a special issue in October 2003 on intellectual disability, genetics and ethics, with Hans Reinders as editor. In his introduction, Reinders, a professor of ethics within a theology faculty, distinguishes two perspectives on the topic from the field of clinical genetics, one internal or within the field, and the other external or on the field itself. The internal perspective comes from patients, doctors, researchers, insurers, and others; it mostly concerns setting moral boundaries. The issue about the right to be informed about family history – and what is morally required, permitted, or appropriate – typifies an internal perspective issue with an internal perspective from clinical genetics. The external perspective looks at the moral underpinnings and examines the moral meaning, not the direct justification, of any one course of action. Some questions from the external perspective are the relationship of the notion of disability to the notion of suffering or to the notion of

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disease. Reinders selected authors from both perspectives to contribute articles, some of which are described below.

One argument on the moral status of the disabled runs as follows. By using knowledge from the Human Genome Project to prevent, ameliorate, or cure genetic disability, the moral status of existing disabled individuals is not diminished. The rationale behind this argument is that families, knowing the risks of their having an affected child, can choose to avoid, start, continue, or terminate such a pregnancy. Genetics counselor Barbara Carmichael objects to that rationale. She believes that the choice-based moral status of the argument is applied almost exclusively to those with learning disabilities, particularly congenital ones.

The choice rationale is based on two medical facts: one, widespread access to accurate genetic diagnosis, and two, the ability to predict accurately an abnormal gene. Medical geneticist Lucy Raymond finds these facts prompt an ethical debate over prenatal testing. Access would possibly increase the overall number of pregnancy terminations of affected fetuses among the population at large, yet accuracy would also decrease the need of an individual family to terminate a pregnancy.

Tony Holland and Isabel Clare, clinical psychiatrist and psychologist respectively, argue that genetics has shifted the moral debate from questions of broader social and cultural issues to the rights of individual choice and self-determination. They propose using human rights as a framework for decisionmaking, in particular as applied to consent and best interest, in

areas such as the right to reproduce, the right to die (or to live, meaning not to abort), and the right to be free from degrading treatment.

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The next three articles have an external perspective on the field of clinical genetics. Philosopher Steven Edwards looks at three theories of the “good life” (hedonistic, preference satisfaction, and ideal), which he argues is the conceptual foundation for the moral justification of prenatal genetic screening for intellectual disabilities. Tim Stainton, a sociologist, finds the moral status of the fetus to be grounded in an “identity-constituting characteristic”, such as disability, the meaning of which is socially constructed and thus political. Jayne Clapton, another sociologist, writes about disability as two discourses, tragedy and catastrophe. By shifting the emphasis from tragedy to catastrophe, she claims that decision-making issues have moved from the private arena to the public one.

In the last article, Chris Goodey takes the historical view, noting that definitions of intellectual disability change over time. He observes that historians do not separate epistemology from ethics, so the search for certainty about intellectual disability is the same search for scientific knowledge and bioethics. That search comes down to the question of how does

one really know, or, stated differently, what are the foundations for knowledge?

The second part of this special issue of the *Journal of Intellectual Disability Research* is made up of three commentaries, and a foreword to those commentaries, on Hans Reinders’ book, *The Future of the Disabled in Liberal Society, An Ethical Analysis* (University of Notre Dame Press, 2000). Professor Reinders questions whether the liberal concept of a meaningful life (autonomy, free choice, the ability to value one’s own life) can co-exist with the structures for the care of people with intellectual disability within a liberal culture. Chris Goodey, Trevor Parmenter, and William Gaventa all take the external perspective on the problem of the value system of a liberal society and the moral resources for the intellectually disabled.

The final section in this issue is a selected bibliography on intellectual disability, ethics and genetics. Herman Meininger, a colleague of Professor Reinders at Vrije University in Amsterdam, edited the original list of over 200 pages into a mere five pages of citations with publication beginning in 1990 and other limitations on content and scope. He divided the citations into seven categories. The six topical categories are: ethics and genetics; ethics, genetics and (intellectual) disability; counseling and consent; philosophical, religious and cultural reflections; attitudes and concepts; and disability, genetics and public policy. The seventh category lists some resources for further research.

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2-4 months until the next hyperammonemia episode, usually during the next infection. Recurrent hyperammonemia will then occur frequently and each time additional brain damage ensues.

When the clinician asks for parental consent for hemodialysis in the newborn period, decision has to be made within an hour. Although the clinical caregivers try to explain that having a baby with this condition will change their lives, the parents are not in a condition to be able to comprehend the information. (They are in a very stressful state and look for advice from us which we don't give — just giving them the options the way we see them). The clinician finds that, in his experience, all parents want him to do everything possible to save the life of their baby. This is what they do, which has become the standard of care. At this stage they know that the next several years will be extremely stressful, feeling like having a "time bomb" that can go off suddenly (hyperammonemia) and would be life threatening. Some families can handle this better than others. The clinician knows he has seen families whose lives have been severely disrupted as a result, causing divorce and serious emotional problems of the siblings who receive less attention due to the attention given to the sick baby. Their lives then circle around how to treat the baby, what to give him/her to eat, and how to prevent the high ammonia levels from returning. Guilt feelings occur frequently. Essentially all the affected infants are mentally retarded and require special-ed and other multiple medical services. Liver transplantation

can cure the high ammonia, which will never return, but it is a tradeoff with complications such as being a risky procedure with probably 10% perisurgical mortality, organ rejection, life-long immunosuppressive treatment required, stunted growth and the long-term outcome for all is thus still unclear, as there may be secondary cancers developed due to long immunosuppression. The procedure is very expensive and may cause economic hardship for the family.

Here is the dilemma as the clinician sees it: How should he approach this issue? Should he incorporate his, and the rest of the clinical care-giving team's, personal ethical beliefs in what they communicate to the parents, knowing that they may be incapable of making a well-informed decision due to their state of mind and due to the fact that they need to decide quickly, as delay in decision would cause the baby to have more severe brain damage or the baby may die? The care-givers believe they are here to preserve the life of their patients, but want the life to be of reasonable quality. What is their responsibility to the family, parents, and sibs? How do they resolve this conflict? They know they have not even touched upon the legal issues involved here.

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Ethics Consultant Robert Olick

As is so often true of heart-wrenching neonatal dilemmas, this case involves both clinical and ethical uncertainty. The parents have the right to decide how their baby should be treated, and the physician should discuss with them the reasonable options, their potential benefits, risks and consequences, including the option of allowing the baby to die. The imminent need to initiate hemodialysis to save the baby's life and avoid more severe brain damage, together with the uncertain longer-term future for this baby, provide sound

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ethical grounds to recommend dialysis and other life-support measures. Under the circumstances, the parents may not be able to make a reasoned, informed judgment but likely will give their permission to dialyze. Personal and professional beliefs about disability and quality of life cannot be entirely excluded from the decisional process, but should not impede a clear and objective explanation of what is at stake for the newborn. The meaning of a future life with intellectual and physical disability, including the associated challenges for the family, is at bottom a value judgment, and one that properly belongs to the parents.

Parental refusal of dialysis presents a more complex set of concerns. If under these difficult, urgent circumstances the

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parents are not capable of considered, informed judgment then to accept their refusal seems ill-advised, even if this course may agree with the physician's own judgment. Preservation of the newborn's life may be required on a strict reading of the "Baby Doe" regulations. These controversial federal rules place limits on forgoing of life-support in the first year of life. However, their application and interpretation in law and policy can vary from state to state, as well as among neonatologists at the bedside. (Some hospitals require involvement of an infant care review committee when forgoing life-support is proposed, though that is impractical in this case.)

These parents will face other life-sustaining treatment decisions in the future with recurrence of hyperammonemia, and possibly whether to seek a liver transplant. They likely will be better able to bear the psychological, emotional and moral burdens of decision and to make informed choices as their child's life unfolds. Ongoing care and treatment of the child should remain sensitive to the demands of decisionmaking in the face of uncertainty and should preserve the parental right to say when enough is enough (at least so long as their decisions are reasonable and ethically defensible). Referring the parents for counseling, perhaps including genetic counseling, should be considered. Arranging a future opportunity to meet with other parents of children affected by this condition may also be worthwhile.

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Carol Taylor

I first want to affirm the ethical sensitivity of this attending who appreciates the power within the physician-patient relationship and who obviously wants to communicate information to the parents in a way that is helpful—without being paternalistic. My sense is that this attending is acutely experiencing the negative consequences of the age of

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autonomy which in too many instances has resulted in respect for autonomy being reduced to non-interference. For example, most attendings would think, "I respect the right of these parents to be self-determining by presenting to them their options in a neutral fashion (NOT by making a recommendation) and then by doing whatever they want." As this attending notes, however, most parents (but by no means all) equate being a good parent and doing the loving thing with authorizing everything medically possible—a choice not always in their baby's best interests!

The object of all clinical decisionmaking is to first secure the health/well being or good dying of the patient, and second, to do this in a way that respects/honors the integrity of

each participant in the decisionmaking process, which in this case includes the baby's parents and professional members of the caregiving team.

We can appreciate two adults confronted with a similar dilemma choosing very different treatment options; i.e., one chooses a course of aggressive therapy even when the burdens of therapy grow excessively burdensome because of the conviction that life lived under any circumstances is precious, and the second chooses palliative treatment at the time of diagnosis because the burdens of treatment seem disproportionate to the anticipated benefits. The question in this case, since we have no way of knowing which course this baby would choose, is how we should decide for the baby. While the attending notes multiple factors which limit parents' ability to make wise decisions, few ethicists would support a return to physicians making these decisions *for* parents. The issue, then, is how professional caregivers can best provide *the information and support* parents need to make wise decisions.

I would strongly recommend that the attending honestly describe what a decision for hemodialysis is likely to entail (both for the baby, and for the parents and siblings) not only in next few days, but in the next months and years. While the bias toward authorizing treatment might justify laboring over the burdens associated with therapy, it is important not to present this information in a way that is coercive toward nontreatment. Presenting this truthfully, objectively, and compassionately, in the interests

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of full disclosure, takes incredible skill. It is essential to communicate that good parents might decide both for and against hemodialysis. Either a decision for dialysis or one against dialysis would be morally within reason if supported by conscientious commitment to do what is best for the baby.

In this scenario the urgency of the decision at hand (one hour) and the life or death consequences of the decision (gravity), argue for a bias toward treatment. If hemodialysis is initiated, the parents need to understand that this decision does not commit them to continue in an aggressive treatment mode in response to complications (stroke, obstruction of vessels, infection) or future episodes of hyperammonemia. At any point they may reach the decision that the burdens of therapy are now outweighing the benefits and choose a palliative course. They may also decide later that a liver transplant is too burdensome to be justified. If the baby's attending will change upon discharge from the hospital, it is imperative that the parents have resources they can contact as future treatment decisions present.

A final caution: It should be noted that this baby's condition does not satisfy the three requirements which the federal Baby Doe regulations cite as the only legal justification for withholding or withdrawing treatment from disabled newborns. The U.S. Department of Health and Human Services rules which were finalized in January 1984 follow.

1. All such disabled infants must under all circumstances receive appropriate nutrition, hydration and medication.

2. All such disabled infants must be given medically indicated treatment.

3. There are three exceptions to the requirement that all disabled infants must receive treatment, or stated in other terms, three circumstances in which treatment is not considered "medically indicated." These circumstances are:

- a. if the infant is chronically and irreversibly comatose.
- b. If the provision of such treatment

If the baby's attending will change upon discharge from the hospital, it is imperative that the parents have resources they can contact as future treatment decisions present.

would merely prolong dying, not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or otherwise be futile in terms of the survival of the infant.

c. If the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.

4. The physician's "reasonable medical judgment" concerning the medically indicated treatment must be one that would be made by a reasonably prudent physician, knowledgeable about the case and the treatment possibilities with respect to the medical conditions involved. It

is not to be based on subjective "quality of life" or other abstract concepts. [U.S. Department of Health and Human Services, "Nondiscrimination on the Basis of Handicaps: Procedures and Guidelines relating to Health Care for Handicapped Infants," Federal Register 49 (12 January 1984): 622-654.]

Numerous clinicians and ethicists have criticized these regulations for their failure (among other things) to take sufficient account of the cumulative burden of multiple physical anomalies and the treatment interventions they require. And thus, while the regulations are still law, their practical effect in guiding treatment decisionmaking at the bedside has lessened. I believe that this baby's parents and professional caregivers might with excellent ethical justification decide on a palliative course of treatment and doubt that there would be legal consequences—although no one, of course, can guarantee that someone would not issue a legal challenge.

Finally, it would be incredibly helpful to have literature to share with the parents. One excellent article is K. Smith and M.E. Uphoff's, "Uncharted Terrain: Dilemmas Born in the NICU Grow Up in the PICU" *The Journal of Clinical Ethics*, 12(3, 2001), 231-238.

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Consent and Persons with Marginal Mental Impairment

By now it is commonplace to rely on consent from a parent or other surrogate when providing therapy or conducting research involving those with profound mental disability. But consent for treatment or research involving those whose intellectual disability is more borderline is presenting some interesting challenges.

In the case of clinical treatment, whether it is medical or psychological, the interest of the patient provides the rationale to rely on a guardian or other substitute for the one whose mental capacity is seriously compromised. That is taken as sufficient reason to permit the surrogate to consent to treatment on the patient's behalf. The patient may object to the surrogate's decision, but, assuming that the treatment is in the patient's interest, the person usually cannot be permitted to override the surrogate. The short-term pain—even of a needle stick—might lead someone to refuse when the treatment is clearly in the person's best interest.

In the case of research using those with profound incapacity, the consent (now often called "permission") of the surrogate is also needed, but, in addition, the agreement of the research subject himself or herself is required—at least to the extent that the person has any capacity to communicate. This approval is now often called "assent" to distinguish it from a formally adequate consent. In research, which is undertaken to produce general knowledge rather than serve the patient's interest, even an uninformed refusal is sufficient to stop the use of the person as a research subject. In a randomized trial involving a placebo, for example, the placebo must be justified on the grounds that we do not

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know whether the experimental drug is better or worse and therefore the placebo does not jeopardize the

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subjects who receive it. In that context it would be logically inconsistent to deny a potential subject's refusal no matter how poorly the person understands.

Those with Borderline Impairments

The situation is much more complicated in the case of persons whose mental impairment is more marginal. Their right to refuse to be research subjects is clear. We grant that right even to the profoundly impaired. But beyond that obvious case, we are beginning to discover some moral perplexities. The fact that the person is on the border between competence and incompetence poses some fascinating dilemmas.

The Clinical Setting

First, in the case of clinical therapy, if the patient is competent—if he or she has capacities and understanding sufficient to be treated as autonomous enough to consent on his or her own, then it is the patient's approval that is needed for therapy,

not the surrogate's. In fact, disclosure of the patient's condition to others without the patient's approval constitutes a breach of confidentiality. Moreover, the patient's informed refusal should be sufficient to stop the proposed treatment—even in the case when the clinician believes that the patient is not making a wise choice.

In the clinical setting the ideal is that the patient be offered all the assistance necessary to help reach an informed choice. Even the clearly competent adult patient should have the opportunity to ask questions, to talk with others, and to involve family members to help the patient in deciding whether to consent. The same goes for those whose competency is more borderline. All patients, including those with borderline competency, should be encouraged to bring family members or friends with them who can help them reflect on the critical choices they must make. As long as the patient agrees to the involvement of others in the choice, some of the difficulties might be avoided.

But suppose the patient whose mental function is borderline is encouraged to involve a friend or relative, but refuses. Suppose that the patient says that he doesn't want his parent or spouse or friend to know about his situation. If we deem the patient sufficiently competent to make his own choices, he ultimately has the right to exclude others from involvement. That could apply even in the case of what appears to the clinician to be an unwise refusal of treatment. Unless the clinician wants to go the route of having the patient declared

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incompetent, there is really nothing that can be done beyond strong advice and encouragement to involve others in the decision.

On the other hand, if the clinician classifies the patient as lacking sufficient autonomy to make his or her own decisions, then involvement of a surrogate is not only wise, it is morally and legally necessary.

The Research Setting

The problem can be even more complicated in the research setting. If the patient is deemed incompetent, then a surrogate's permission is needed as well as the patient's assent if she is to be a subject of a study. But in the case of borderline competencies, some patients will be deemed competent. They then not only have the right to refuse to participate; they also have the right to consent to participation. In the extreme case, they even have the right when the nearest caregiver, friend, or family member objects. In fact, these well-meaning potential surrogates do not even have a right to be informed of the offer to the potential subject (unless the subject can be persuaded to approve of involving an "advisor").

In the most troublesome of cases, a mentally impaired, but borderline competent person could consent to (and insist on) participation in research that could not benefit the patient even over the vociferous objection of the closest and most caring family members.

This poses an interesting moral dilemma for professional caregivers committed to research designed to

produce general knowledge that could improve the lot of those with mental disabilities. They want to do the research; they want to benefit people like the potential subject. They might be able to obtain the consent of the competent but impaired person, but face the objection of the family member or the awareness that the closest relatives are not aware of the impaired person's involvement. The researcher

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may honestly want to provide all the assistance that could help the potential subject decide (including the involvement of family members) but also want to respect the individual as a substantially autonomous (if impaired) person with rights of confidentiality and self-determination. The story is complicated by the fact the researcher also wants to recruit subjects for the study and has something of a conflict of interest in encouraging the person to seek involvement of friends or family.

Strategies for Coping

Some institutional review boards are dealing with this problem, including the independent, free-standing Goodwyn IRB of which I am a member. Our first decision was to recognize that a formal assessment of competency was required—not just a seat-of-the-pants judgment about whether the potential subject was competent. We

insist on some formal assessment tool. We recommend the use either of a tool we have created or the *MacArthur Competence Assessment Tool for Clinical Research*,¹ but are open to researchers who want to propose other alternatives.

The second step is to realize that those with mental disability have a right to be treated with respect. That includes acknowledging that those with borderline impairments may nevertheless be sufficiently competent to make their own choices and that, if they meet that test, they have certain rights of privacy as well as rights to being adequately protected from risks of harm.

The third step is developing approaches that treat competence as a contingent concept. It is contingent on the nature of the decision to be made and the difficulty in understanding what is being proposed. Some scholars also believe that competency should be treated on a sliding scale—that a higher standard of competency must be met for decisions where more is at stake.

Finally, those in a position to assess competency must realize that the patient's or subject's competency may change from time to time. In fact, the treatment intervention itself may improve or make worse the patient's capacity to make decisions to consent to therapy or research.

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