INTRODUCTION

Contemporary bioethics arose in the 1960s in the wake of innovations in dialysis, transplants, artificial organs, and assisted reproduction. These biotechnologies sparked debates about the allocation of scarce resources and the quality and limits of life. In response, ethicists developed a set of abstract normative principles—autonomy, beneficence, and distributive justice—which structure professional debates to this day. These core principles of American bioethics take a generic concept of the person and make it the basis for a universal morality. This is, of course, the autonomous individual of Western liberalism: the sovereign individual who acts freely according to a self-chosen plan. However, the very technologies
that sparked early bioethics unsettle this tacit understanding of the person. They have created new ways of exerting one's will and gauging one's present identity and future fate. For example, predictive genetic testing alters the way people calculate their life prospects—the likely mixture of happiness and suffering they will encounter—and it can erase or intensify certain aspects of their identity. New strategies to assess people's subjective experience are demanded by transplantation and mechanical ventilation. Such technologies set in motion profound transformations in our cultural model of personhood and in the ways we experience and enact moral agency. These transformations, as much as the conflict between abstract principles, motivate our deepest ethical concerns.

This article takes up a vexing tendency in our current use of biotechnologies: the replacement of moral discourse by technical expertise. This tendency is magnified when health care professionals must make educated guesses about the subjectivity of technologically altered individuals. If we regard biotechnology as a simple collection of devices—a morally neutral means to the ultimate good of prolonging life—certain procedures become a standard, unquestionable component of care (1). This, in turn, justifies technical discourse as the sole guide for treatment decisions. It provides certainty for medical workers, but it also rules out other ways to understand the experience of, for example, chronically ventilated children and our ethical obligations toward them. This article examines the conflict of interpretation over the subjective experience of the mechanically ventilated child. Too often, the authority to read it one way or the other remains solely in the hands of medical professionals, illustrating how rational, technical expertise can foreclose genuine moral debate.

PROLONGED VENTILATION FOR CHILDREN WITH NEUROMUSCULAR DISEASE

An infant or young child with a neuromuscular disorder, such as nemaline rod myopathy or spinal muscular atrophy, usually presents with generalized poor muscle tone, which then progresses to respiratory failure and the need for assisted ventilation. Often a muscle biopsy is necessary to make a diagnosis, and the first biopsy may be inconclusive as it takes time for the characteristic pathological findings to develop. Nemaline rod myopathy, selected as an illustration of the issues raised in this entry, is a rare and slowly progressive neuromuscular disease that renders a person immobile (2,3). Unable to move and unable to breathe, such an infant may undergo a tracheostomy procedure so that the airway is secure and the infant can be ventilated more easily. A tracheostomy, which is a plastic tube inserted into the windpipe through a surgical incision in the front of the neck, is done when the plan is to provide long-term ventilation, perhaps including sending the patient home on a ventilator. In addition a so-called gastrostomy tube may be placed into the infant's stomach through the abdominal wall so that the infant can be fed without placing a temporary feeding tube through the nose. Once these procedures have been performed, the infant is often transferred from the intensive care unit to a "step-down" unit designed for long-term care and is placed on a simpler breathing machine whose primary purpose is for use in home ventilation.

We do not know what causes nemaline rod myopathy, nor do we have any treatment for it other than putting someone on a ventilator. It only affects the skeletal muscle, so the other muscles of the body such as the heart and gut work fine. In its most severe form, the child cannot move, cannot swallow, cannot breathe, and may not be able to move his eyes or close his eyelids. Eyes open and barely moving, an affected infant or child will stare at you without expression, unable to move the muscles of the face to show pain or pleasure, unable to smile or frown, unable to laugh or cry, unable to communicate at all—the face a frozen, expressionless mask. The disease, however, does not affect the brain. An affected infant or child is alert and aware of everything going on around him.

At times, conflict may arise over the continued use of mechanical ventilation, with a parent insisting on the right to remove the ventilator and let the child die, and the professional staff (both nurses and physicians) resisting or disputing this claim. Usually this conflict is addressed in such terms as the child's quality of life, the "value" of living with a severe disability, the child's "best interest," the authority of the physician/state in determining "medical neglect," the parent's authority to make decisions concerning the child's medical care, and so forth. All of these approaches assume that the technology itself is morally neutral: It sets the stage for ethical conflict but does not influence the outcome. In this article we question that assumption. We suggest that once biotechnology is introduced into patient care, it constrains our subsequent moral choices, and this belies the claim that the technology itself is morally neutral. We examine, in particular, tracheostomy and mechanical ventilation, techniques that undercut parental (or nonprofessional) control over the medical care of children suffering from a neuromuscular disease such as nemaline rod myopathy. Because medical professionals control both how to use these technologies and how to interpret their effects upon individual subjectivity, ethical conflicts become prematurely translated into matters of technical expertise.

To examine these issues in the case of a ventilator dependent child, we need to understand how the technology affects the child, how the ventilator defines and redefines the boundary of body, and how the ventilator produces a subject who is both body and machine. Rather than a neutral technology designed to achieve goals that are selected for non-technical reasons, the ventilator seems to impose its own agenda and values. However, we should not reify this technology in a way that obscures and thus privileges the agency of the medical professionals who control it—as in the Wizard of Oz when we are told "don't pay attention to that man behind the curtain." Moreover, we need to pay attention to the organizational and cultural context within which professionals operate. Only then can we understand how professional power infiltrates both the use of technology and the interpretation of its effects.
MEANING OF TEARS

An infant with nemaline rod myopathy often has tears in his eyes, lending support to the belief (usually by a parent or family member) that this constant tearing indicates emotional and physical distress. The professional staff, however, may interpret these tears as a simple result of an inability to close the eyelids, rather than a reminder of an infant’s suffering. Such an infant becomes the locus of a contested interpretation. The parents view the infant as too fragile and unable to tolerate activities such as being propped up in a wheelchair or taken out of the hospital on field trips. The apparent suffering of the infant often motivates their desire to stop the ventilator at some point in the future. The staff regards the infant as able to take pleasure in simple things and to sit contentedly in a chair for hours. On occasion, the staff may blame a parent for the very episodes that the parent interprets as fragility, arguing that the infant would cry when his parent arrived and “suffocated” him during a brief visit. This conjures up the image of an overprotective parent who fails to appreciate the strength and ability of her or his child; however, the use of the metaphor of suffocation takes on a more literal and provocative meaning given the staff’s suspicion of the parent’s (implicit or explicit) desire to stop the ventilator.

Fundamentally the infant’s parent continues to see the ventilator as something other than the infant: as a threat, as an invasion of his body, as something foreign. Removing it in order not to prolong the infant’s suffering simply returns the infant to a more natural state. In the eyes of the staff, the threat to the infant is not the ventilator but the parent. The staff often regards such an infant not as a body on a machine, but as both body and machine—that is, a machine-human/machine cyborg (cybernetic organism) whose body and machine components are mutually interdependent. Therefore, to ask the staff to participate in turning off the ventilator is to ask them to amputate part of the infant’s body. Is there a fact of the matter that could settle this dispute about removing the ventilator? Is there a third point of view, acceptable to both parties, from which the relationship between tears and suffering could be “objectively” determined? Glossing the difference between pain and suffering, the absence of other signs of pain such as sweating and a rapid heart rate may support the staff’s argument. This is an argument that a parent can only lose; the best one could hope for is for everyone to agree to disagree.

There often is no apparent disagreement over the moral principle that mechanical ventilation can be stopped if the burden of such treatment outweighs the potential benefit. What is in dispute is the description of the child as either suffering or simply unable to close his eyelids. The staff is able to substitute a physiologic argument about the presence of pain for the existential question of whether the child is suffering—in effect, shifting a moral argument about the worth of living life on a ventilator to a technical dispute about the interpretation of a physical sign. In addition the staff has the political power to threaten a parent with a charge of failing to provide necessary medical treatment, that is, “medical neglect,” thus throwing the matter into court. Consequently the moral and political questions about what to do are transformed into a rational technical discourse that in the minds of the staff is unambiguous. As such, the dependence of knowledge on subject position or “point of view” is implicitly denied; the power to determine objectivity is invisibly exercised. Rather than moral and political discourse about the conflicting visions of the infant’s experience serving as the “paradigm of rational discourse,” the professional technical discourse determines the political stakes and reduces moral discourse to the vanishing point.

KNOWLEDGE AND COMMUNICATION

An appeal by the parent to the shared “sense experience” of the child’s tears usually will not persuade the staff that the child is suffering. In addition the staff will probably fail to convince a parent that the child’s tears simply mean that he cannot close his eyelids. The staff may additionally dismiss the parent’s claim to know that the child is suffering as mere subjective opinion. The staff’s insistence that the child is not suffering clearly reinforces their professional interest in continuing treatment.

In answer to the question—“What protects knowledge from being [either] the arbitrary expression of subjective desires [on the part of a parent] or the tool of social and personal interests [on the part of the medical and nursing staff]?”—Helen Longino, a philosopher of science at the University of Minnesota, offers an approach she refers to as “contextual empiricism.” Longino, as do other philosophers in the pragmatic tradition, grounds “objectivity” or the truth of a statement concerning a sense experience in an “inter-subjective” or “social” process that should ensure “the inclusion of all socially relevant perspectives in the community engaged in the critical construction of knowledge” (7, pp. 200, 202–203). A necessary part of this communicative process is a critical examination of the implicit assumptions that establish the relevance and interpretation of observational or empirical data. The natural world cannot impose one single interpretation, that is, the empirical observation of the presence of tears does not establish the truth of one or the other interpretation. However, differences of power in this social or communicative process may limit the plurality of interpretations to the one that is consistent with the dominant discourse.

This is the outcome, for example, when a particular powerful group or individual constrains the freedom of expression and diversity of legitimate knowledge, or restricts the community of discourse in such a way as to predetermine which interpretation is accepted. This process involved (fragment) discounting the parent’s interpretation of a physical sign such as an infant’s tears. Parents may also be isolated from outside family and community supports and effectively alone with the medical staff during conversations in the hospital about the care of their child. In this setting medical professionals fail to establish a meaningful community of inquiry concerning the question of a child’s suffering.
In discussing contemporary policy debates about technology in general, Langdon Winner observes that this lack of a coherent community of discourse "contributes to two distinctive features ... (1) futile rituals of expert advice and (2) interminable disagreements about which choices are morally justified" (8, p.75). The moral uncertainty involved in the application of ventilator technology to the indefinite support of patients cannot be resolved by an appeal to the technical advice and expertise of the physician. Such a "futile" appeal to expert advice will not achieve a consensus. Moreover the lack of an appropriate community of discourse and the resulting disagreement over what choices are morally justified privileges the physician's technical expertise and thus interpretation of the patient's experience. While this does not avoid a conflict of interpretations, it guarantees that the conflict gets resolved in ways that favor the power and interests of the physician.

KNOWLEDGE AND POWER

In response to this professional prerogative which constrains the available choices, how do we empower a parent to make decisions concerning her child's medical care? The notion of personal autonomy or self-rule has resulted in a significant shift of power from the physician to the patient over the past two decades. However, once we abandoned the concept of the child as property, the notion of parental autonomy as a justification for the right of a parent to direct a child's medical care became problematic. Each one of us may have an absolute right to determine our own medical care. A parent has, at most, a prima facie right that is limited by the child's right to life and freedom from serious bodily injury or disability (9). Within this constraint we expect that a parent will make decisions that benefit the child or, in other words, are in the child's "best interest." Thus the parent's vision of the good is imposed on or becomes the child's vision — an imposition we accept given the diversity and, at times, incompatibility of competing visions of the good within our society. This creates a disturbing paradox. On the one hand, we expect a parent to express a decision concerning his or her child not as "what is good for the parent" but rather as "what is good for the child." On the other hand, the only possible way to give "voice to the voiceless" is by articulating adult values and projecting them upon the child (10). An infant with nemaline rod myopathy cannot speak; so when we speak for such an infant, we ask: "If I (the adult) were in this condition, what I would want?"

If we seek to escape this paradox and avoid this imposition of adult values by supporting the child until he is capable of self-expression, we inadvertently reinforce the physician's tendency for the relentless application of life-sustaining technology. Consequently the concept of a child's "best interest" appears to be the arena for an unavoidable expression of adult power on the part of either the physician or the parent. The stakes are high, for if the parent understands the child's "best interest" in such a way as to refuse what the physician otherwise believes to be necessary medical care, the parent may find him- or herself in court facing a charge of medical neglect.

The past two decades have seen a lively debate in the bioethics literature and the courts concerning the withholding and withdrawal of life-sustaining technology (11). Some have argued that removing a person from a ventilator is to choose death based on the judgment that the anticipated quality of life is not worth living. Others, concerned about the potential abuse of quality-of-life judgments, have argued that such decisions are better understood as the choice of how to live while dying (12) or as simply the decision to remove technology that is no longer medically indicated (11,13). The first argument, that of how to live while dying, makes the decision to remove a ventilator dependent on a prior determination that the patient is dying — a determination that the technology itself makes more difficult. A child with nemaline rod myopathy who is on a ventilator may not die for years in the absence of an intervening complication. Thus, once you put him on the ventilator, you cannot remove it unless he is dying, and he is not dying unless you remove the ventilator. The second argument, that technology can be removed when it is no longer medically indicated, either restricts the removal of technology to those situations where more narrow technical goals cannot be achieved or obscures the physician's own determination of an acceptable quality of life behind the veil of professional technical competence. A ventilator is medically indicated when a patient has respiratory failure; it is not indicated when either the patient recovers or the ventilator fails to correct the respiratory failure. Thus, in most cases, the ventilator for an infant with nemaline rod myopathy is medically indicated. If a physician argues that the ventilator is not medically indicated, since correcting the patient's respiratory failure does not contribute to the overall good of the patient, we necessarily must engage the question of what is or is not in the patient's "best interest" — a discussion that cannot avoid questions of the patient's quality of life. The problem then of trying to avoid an explicit discussion of a child's anticipated quality of life is that the physician's power and authority is inadvertently reinforced.

Physicians impose their power by establishing what counts as legitimate and credible knowledge, rather than by forcing a choice for one of either two credible options. In asking whether a child on a ventilator is suffering, a parent and the health care team may disagree over the description of the child's life, not over the moral evaluation of an agreed upon description (14). It is simply not credible to the medical staff that the child is suffering. In discussing the problem of technology as ideology, Robert Pippin asks whether we have "been so influenced by technical instruments ... that our basic sense of the natural world has changed ... so fundamentally that ... possibilities for social existence are seen only ... in terms of such technical imperatives." The physician's reliance on technology "reaches a point where what ought to be understood as contingent, an option among others, open to political discussion, is instead falsely understood as necessary; what serves particular interests is seen, without reflection, as of universal interest; what is a contingent, historical experience is regarded as natural" (15, p. 46). Physicians appear to have lost any sense of the natural or the contingent as a moral category. Rather the natural
serves to mark that domain that resists the physician's intervention, as in "let nature take its course." The natural becomes that which cannot be technically overcome, rather than that which should not be overcome. The natural is subordinated to the technical, which in turn resists the explicit introduction of moral and political questions.

**DIFFERENCE BETWEEN STARTING AND STOPPING**

The belief that technology is a neutral means to whatever ends are selected on moral, political, or more narrow physiologic grounds is a fundamental conviction and ideology of medical practice. For example, the decision to perform a tracheostomy may not be intended as a decision for long-term home ventilation but may be seen as consistent with a desire to defer any decision to limit or withdraw support given any remaining uncertainty about a child's diagnosis and prognosis. A parent may be told that a decision to perform a tracheostomy does not preclude a decision at some point in the future to remove a child from the ventilator—"what is done can be undone." Such a statement is consistent with the widely endorsed bioethical teaching that there is no significant moral or legal difference between withholding and withdrawing treatment (11).

There are a number of important assumptions behind the use of this bioethical maxim. First, it assumes a symmetry in the application and removal of medical technology consistent with the prejudice that technological means are value-neutral. It also assumes a symmetry between an endotracheal tube and a tracheostomy by reducing each to its essential function of establishing an airway for the purpose of mechanical ventilation. However, as an endotracheal tube is inserted either through the mouth or nose, the tape required to hold it in place covers a major portion of the face. A tracheostomy surgically inserted through the front of the neck results in the entire face being visible and thus capable of expression. Second, the maxim appears to ignore any relevant differences that may occur between the moments of application and removal of the technology, apart from any changes in the medical indications. Third, and related to this historically naive stance, is the view that the organizational context in which these decisions are being made is apparently unimportant. After a tracheostomy, a child may be transferred out of the intensive care unit and to the ward that houses patients in the home ventilation program. One wonders whether the use of this bioethical maxim that there exists no significant moral or legal difference between withholding and withdrawing treatment is based on a reasoned ethical stance, or used as a rhetorical device to postpone the discussion of more difficult ethical issues to a later date. The latter interpretation is confirmed, for example, when a receiving physician in conflict with a parent over the removal of a ventilator is unable to find any other physician willing to assume the child's ongoing medical care (and thus agree to withdraw support), including any of the physicians who have previously cared for the child prior to the tracheostomy. An appreciation of the value-laden nature of a tracheostomy, along with the importance of time and context, counsel against a premature surgical procedure and then transfer to a home ventilation program.

**IS TECHNOLOGY VALUE-NEUTRAL?**

The bias that our medical technology is simply a "collection of devices" emphasizes the functional aspects of technology and obscures its social context. As a result of this dichotomy between function and context, our technology appears value-neutral, while only the application of that technology becomes morally problematic. Andrew Feenberg, in an article reflecting on the relationship between technology and power, points out that this "dichotomy of goal [function] and meaning [context] is a [contingent] product of functionalist professional culture" rather than a necessary component of technology (16, p. 9). Echoing criticisms of the common view of science as value-free, Feenberg asserts that this ideology of technology as value-neutral reinforces the dominant forms of power that compose the cultural horizon and social meaning of technology. Feenberg refers to this as the "bias of technology" by which "apparently neutral, functional rationality is enlisted in support of a hegemony," that is, the professional dominance of those who control the technology. The professional claims to exclusive control of technology are strengthened insofar as its associated values and presuppositions drop out of sight (16, p. 12).

This professional control is also reinforced by the perception that technology should always be used when it can be used: the so-called technological imperative. Barbara Koenig suggests that the technological imperative acquires a certain moral force as the technology becomes habitual or routine (1). Her field research focused on therapeutic plasma exchange, a procedure that involves the removal and then replacement of blood plasma. Koenig identified three steps in the process by which plasma exchange became a routine therapy for certain conditions. The first step was a transformation in roles and responsibilities. The physician–nurse relationship shifted from egalitarian to hierarchical while, at the same time, the physicians moved from being closely involved to delegating many of the routine tasks to nurses (1). Similarly the physicians involved in a home ventilation program maintain close control while shifting many of the routine tasks from in-hospital nurses and respiratory therapists to parents and visiting home nurses. The second step was the use of treatment rituals that appeared to reduce uncertainty, anxiety, and disorder and thus established the meaning of the technology as standard therapy for both patients and staff (1). When a patient is placed on a home ventilator after a tracheostomy, there is an orderly and nearly invariable process of parental training, arranging for nursing services, equipment purchase, and so forth, that must take place prior to discharge from the hospital. Any deviation from this process generally results in uncertainty, inefficiency, omissions, and the like. The third step that Koenig identified was the generation of research data. Noting the enthusiasm with which the physicians engaged in plasma exchange collected clinical data as part of their ongoing research, she speculated that the machine's capability
of producing research data supported the physician's tendency to use the technology (1). Although this may be true with therapeutic plasma exchange, it does not appear that the development of home ventilation programs was driven by a research imperative. The physician's use of home ventilator technology is more likely driven by such factors as the need to find alternative placements for children who otherwise would survive intensive care but remain dependent on ventilator technology. Also the immediate efficacy of the ventilator when compared to plasma exchange is obvious, for otherwise the child would die. Despite these differences Koenig's conclusion remains essentially correct. The technological imperative is transformed into a moral imperative through the development of a "sense of social certainty experienced by health professionals" (1, pp. 485-486). The technology simply begins to feel routine, and hence both appropriate and necessary.

The decision to perform a tracheostomy and then to transfer a child to a unit where the use of chronic home ventilation is considered routine is governed by a similar moral imperative. The unit is organized so that home ventilator technology is accepted as standard therapy. Within this social context, it becomes difficult, if not impossible, to question whether this technical standard of care ought to be used for any particular child. The moral question of what is in a particular child's "best interest" thus receives an axiomatic answer applicable to all children: "Given these circumstances, we should provide the standard technology." The moral meaning of our medical technology is thus created and sustained by the professional culture of the hospital. Since the statutory definition of medical neglect in Wisconsin, for example, is simply failure to provide necessary medical care, the technological and moral imperative experienced by medical and nursing professionals clearly has "the potential to wrest control of decisions about the use of technology" from parents and patients (1, p. 489).

Andrew Feenberg proposes that one of the assumptions behind our modern image of technology is that social institutions must adapt to the technological imperative. Noting that "the economic significance of technical change often pales beside its wider human implications in framing a way of life," Feenberg encourages us to study the "social role of the technical object and the lifestyles it makes possible" through defining "major portions of the social environment, such as ... medical activities and expectations" (16, p. 9, 16). This assumption that we must adapt to technology is readily apparent over the past two decades with the development of home care programs for so-called technology-dependent children (17). The family is explicitly expected to change in response to the demands of caring for a child who is to be discharged from the hospital on a home ventilator. The only other available option is foster care, which is problematic for two reasons. While the child is in foster care, a parent may lose control over any decisions to either withhold additional medical treatment or withdraw existing medical treatment. In addition there is often an unspoken assumption that to choose foster care reflects poorly on the ability of a parent to provide for his or her child. Although many parents choose to take their ventilator-dependent child home out of a sincere concern for their continued life and well-being, the normative pressures against choosing otherwise are enormous once the child is within the context of the home ventilation program. This assumption that social institutions such as the family must adapt to the technological imperative is another manifestation of the extension of professional power implicit in the ideology of value-free technology.

The apparent inevitability of the technological imperative is rejected by both Koenig and Feenberg. Consistent with Koenig's thesis, Feenberg asserts that "technology is just another dependent social variable" and the "scene of social struggle" (16, p. 8). Contrary to the claim that technology itself requires professional control, Feenberg argues that technology has been used to block the extension of public or democratic control to "technically mediated domains of social life" (16, p. 20). Thus the professional medical culture seeks to reinforce the image of technology as both value-neutral and complex in order to maintain control despite the "routinization" process of placing that same technology into the home.

CONTESTING POWER OVER TECHNOLOGY

To insist that technology is "socially constructed" may give the impression that people ultimately hold complete power over its meanings and uses. The typical circumstance of one group having more control and another group having less control over technology results, in this view, solely from social and political considerations independent of the constraints of particular devices. To deny that technology is "socially constructed" may imply the opposite extreme: that we have no power over technology and that our moral and cultural response is determined by its concrete and independent reality. We argue against both extremes. To assume that technology is neutral—the core of the anticonstructionist position—reinforces the professional dominance of physicians. By failing to recognize the extent to which technical knowledge is constructed by and for the interests of a particular community, we are likely to ratify this group's power and authority. At the same time the strong constructionist position ignores the material effects of this technology and the way it constrains moral deliberation. By use of this technology, a child's breathing becomes, ineradicably and by definition, assisted breathing. As a result the object of clinical decision making has become altered. It is no longer the child as such but the hybrid object of the ventilator/child. Once this massive technological intervention has taken place, it is not clear who gives life to whom: the ventilator to the child, or the child to the ventilator? In the face of this ambiguity, medical workers substitute technical rationales for action (algorithms and expertise about ventilator use) for the search for mutual understanding about the child's experience and, possibly, suffering. In the end this process makes humans subservient to things (18). However, this result is produced by both the social power of the profession and the particular way this technology transforms the very objects of clinical decision-making.
Cleaving to either the strong constructionist or the strong anticonstructionist position misses this complex result.

Controlling the technical mediation of social activities such as medical care is a major source of public power within our society. The ability to manage or expand this technical mediation results in the concentration of power in an elite group of experts, the narrowing of acceptable options for public discussion, and an increase in the extent of administrative or professional control over aspects of daily life (15). Changes in the way medical technology is delivered or applied to a particular problem will require a shift in this expert control of technology. As Feenberg writes: "If authoritarian social hierarchy is truly a contingent dimension of technical progress... and not a technical necessity, then there must be an alternative way of rationalizing society that democratizes rather than centralizes control" (16, p.5). Is the link between the physician's social role and the control of medical technology necessary or contingent? For example, one approach to the issue of physician-assisted suicide is to allow for assisted suicide while preserving the traditional social role of the physician by making available to the general public the technical tools that to-date remain under the physician's prescriptive authority.

If we move the control of medical technology into the public domain, we will need to create an appropriate community of discourse to monitor development and application. Such a task may be difficult given the diversity of our current communities. Although the reform of technology is a better option than simply resistance, it is not clear that those (e.g., nurses and physicians) who have been socialized in the modern medical ethos could resist attempting to impose new forms of professional control (15). The creation of a community for the reform of medical technology should include those who anticipate needing or who may resist medical technology and thus will require abandoning the notion of professional expertise. In addition such a community of discourse must begin by questioning the assumption that technology is a value-free instrument—an assumption that serves to reinforce professional control and hinder rational debate. Or should we simply recognize the legitimate existence of disparate communities and thus reframe the question of the appropriate application of medical technology as a choice of which community to belong to?

**BOUNDARY OF BODY**

Let us now return to the question of whether the medical and nursing staff simply see a mechanically ventilated child with a tracheostomy differently than he is seen by his parent(s). As the disease progresses, a child with nemaline rod myopathy cannot move, cannot breath, cannot express emotion, indeed cannot make any facial expressions; communication at best may occur through the movement of an eye in response to a question. Consequently it may be difficult if not impossible to get any indication of what a physical sign such as "tearing" meant to the child. As the passive object of our application of ventilator technology, the child is reduced to either a resource for our instrumentalist projects or a mask for our dominant interest in maintaining control (6). Modern medical technology, as we have seen, clearly includes the feature of the technical control of some human beings by others. Donna Haraway attributes this modern tendency towards technical domination to the dualism between objective nature and subjective culture so that the projects or interests that shape our determination of natural objects are hidden from view. As an alternative, she offers us a view of "objectivity as positioned rationality" (6). To capture a notion of the object as active and not passive, Haraway asserts that "bodies as objects of knowledge... materialize in social interaction. Boundaries are drawn by mapping practices; 'objects' do not pre-exist as such" (6, p.200–201). The issue then is the various positions from which each one of us, including the child's parents, view the ventilated child—a question that necessarily draws us back into an explicit discussion of the power of professional "mapping practices" in determining the boundaries of the ventilated child as the object of our attention.

How then are we to understand who the ventilated child is, this body attached to a ventilator? Through an exploration of the "semiotic use of the body" among the Kayapo of the Brazilian Amazon, Terence Turner illustrates how "the body is at once a material object and a living and acting organism possessing rudimentary forms of subjectivity that becomes, through a process of social appropriation, both a social identity and a cultural subject" (19, p. 145). For example, the Kayapo use various modifications of their body surface to define and redefine their social identity, as in the use of ear piercing to indicate age cohort, marital status, and other social identities. The individual Kayapo, as both a social body and an embodied subject, assumes the dual role as product and producer (19). In our case the body of the ventilated child as a material object of our technical interventions takes on the social identity of a patient in the home ventilation program. Although his parent(s) may try to resist this medical appropriation of the child's body, the tracheostomy and attached ventilator tubing are key modifications of his body that produce the child's social identity as a patient in the home ventilation program (19). The ventilator-infant as embodied subject appears to be the socially patterned product of our technical activity, rather than the producer of its own activity. Similar to the ideological consequences of the view of technology as value-neutral, the misrepresentation of the "cultural subject" of the ventilator-infant as an "objective (natural) feature existing independently" of our social production further reinforces the dominant power of the physician (19). In infancy, it is unclear that there is any content to the notion of the subject existing prior to and independently of the social production of the embodied subject by others. In other words, what meaning can we give to the notion of the "best interest" of the child apart from the specific interests of a particular embodied social subject? Once a child undergoes a tracheostomy and is placed on a chronic home ventilator, he is and will remain a patient in the home ventilation program. This much is visibly announced on his body. Thus we come full circle to the notion of the ventilator-infant as cyborg, the machine-human as "embodied subjectivity" rather than the machine as external to the body. The
social identity of the ventilator-infant/infant-ventilator is a product of being a machine-human hybrid, that is, the ventilator gives life to the body and the body gives life to the ventilator. To contemplate taking the patient off of the ventilator would be to contemplate amputation—a request that the medical and nursing staff cannot and will not honor.

CONCLUDING REMARKS

What have we learned from this story of the social production of the ventilator-infant as a patient in a home ventilation program? We have come to doubt the universality of the classic teaching of the symmetry between withholding and withdrawing technology. We have a renewed understanding of the insight that our medical technology is not value-neutral, and that it often serves to reinforce the professional dominance of physicians. While we acknowledge that specific hospital units have different cultures, the general impact of the organizational context on the ability of patients and parents to control the application of medical technology is greater, on reflection, than previously appreciated. This impact occurs not primarily through the imposition of a different set of moral values, but through fundamental shifts in our point of view, and thus how we see and come to know our patients. The fundamental conflict between medical staff and the parents of young, chronically ventilated children does not turn on a choice between competing ethical principles. As we have seen, medical staff often do not advance any explicit ethical principle in support of their action (i.e., refusing to withdraw the ventilator). The conflict turns rather on what counts as the proper object of concern: the child, the ventilated child, or the hybrid “ventilator-child.” In this conflict, medical workers enjoy enormous power to make authoritative readings of the child’s subjective experience and, more generally, what is admitted as knowledge in the medical setting.

Using the example of ventilator technology, this article demonstrates how the use of biotechnology constrains our subsequent moral choices concerning the application of that technology in a manner that belies the claim that the technology itself is morally neutral. Physicians and other medical staff are thus “technicians” in the following sense: They translate moral and political issues surrounding the application of biotechnology into the dominant technical discourse. To accomplish this, these technicians may constrain the freedom of expression and diversity of legitimate knowledge, or they may structure the community of discourse in such a way as to reinforce their own power and interests. Whatever strategy they ultimately follow, the ideology of technology as value-neutral reinforces their dominance in the clinical encounter and their authority to establish the local meanings of technology. The belief that biotechnology is a value-neutral means to certain ends selected according to entirely different criteria (moral, political, or physiological) thus perpetuates professional dominance over patients and their families. Moreover this belief obscures that the process is happening at all. Clinical actions, such as withdrawing or continuing ventilation, as well as knowledge claims about the child at the center of attention, are always underdetermined by available physiological evidence. Ethics and politics, even if hidden, play the crucial role in the outcome of conflicts between medical staff and parents. Elucidating that role, and restoring moral discourse where it has been banished, demands that we abandon the model of morally neutral biotechnology.

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BIBLIOGRAPHY

INTRODUCTION

Surveys can provide a useful baseline for policy planning, educational development, marketing, and ethical discussions. Surveys may include the general public or may seek to identify the views of various stakeholders, such as researchers, physicians, genetic counselors, or patients. Surveys also have limitations. This article will present the rationale for doing surveys, outline major types of survey methods, and describe some results of major national and international surveys of public and stakeholder views on biotechnology, including genetic testing, screening in the workplace, gene therapy (including germ-line gene therapy), and enhancement of average human characteristics.

RATIONALE FOR CONDUCTING SURVEYS

Uses of Surveys

Surveys can be useful in providing a baseline for public policy debates or ethical discussions, devising educational programs, marketing genetic services, and identifying existing or potential abuses of genetics. In the public policy arena, for example, it makes little sense to outlaw a test or procedure that most people would either use themselves or think others should have a right to use. Policies related to abortion for fetal "defects" are one example. The General Social Surveys (GSS) conducted by the University of Chicago's National Opinion Research Center on a random sample of the United States adult public have indicated that about 80 percent believe a woman should be able to get an abortion if there is a "serious defect" in the fetus. This percentage has varied by only a few points between 1971 (two years before Roe v. Wade, the Supreme Court decision legalizing abortion) and 1998 (1). Reports such as this can be useful to lawmakers, courts, advocacy organizations, and lobbyists. Surveys have the advantage of allowing a wide variety of people to express their views, including many who would not otherwise come forward to comment on proposed policies, regulations, or ethical guidelines.

In the arena of education, surveys can identify areas of ignorance that may require special educational programs. For example, a 1986–87 survey of 1473 physicians conducted by the U.S. Congress Office of Technology Assessment (OTA) found that 63 percent would reject a sperm donor with a family history of Huntington's disease (an autosomal dominant disorder with severe effects on the nervous system, transmitted to 50 percent of the offspring and not presymptomatically diagnosable in the donor at the time), while 61 and 49 percent respectively would reject a healthy donor with a family history of Duchenne muscular dystrophy or hemophilia A, both of which are transmissible only by females (2). The survey results indicated need for better education of physicians, greater oversight by sperm banks, and new guidelines from professional societies. A 1995 survey of 499 U.S. primary care physicians found that substantial percents held inaccurate knowledge about the life expectancy and functioning of people with common genetic disorders such as cystic fibrosis or Down syndrome (3).