Chapter 1
Tortured Bodies, Tortured Doctrines: Informed Consent as a Legal Fiction Inapplicable to Neonatal Male Circumcision

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Abstract The doctrine of informed consent functions reasonably within its area of applicability of competent adults, though even in that setting it suffers from some difficulties both theoretical and practical. When applied by proxy to incompetent persons such as mentally incapacitated adults and newborn babies, the doctrine becomes a legal fiction, i.e., a legal construct created to force-fit a set of facts into an established legal analysis that is not literally applicable. The conceptual, ethical and practical difficulties are maximized with proxy permission to authorize circumcision of neonates. "Proxy consent" for neonatal circumcision is a legal fiction that cloaks a usurpation of agency allowing ostensibly hallowed principles of autonomy and self-determination to be violated with impunity. Such legal fictions conceal our violations from ourselves and others under the pretenses of legal authorization and compliance with ethics and human rights, and—in the circumcision context—the further pretense of medical authorization, masking our failure to properly safeguard human dignity and autonomy.

Keywords Circumcision • Human rights • Law • Torture • Informed consent • Proxy consent • Medical ethics

1.1 Introduction

Legal fictions are artificial constructs created by the law to facilitate fitting the circumstances of a particular case into an established legal analysis to which the facts do not strictly conform. For example, the legal fiction of implied consent to a blood alcohol level test is imputed to drivers in certain states. No actual consent has been given, but according to this legal fiction, consent is deemed to have been given by the act of driving on the roads in one of these states. The doctrine of informed consent—the idea that the competent patient has the right to give or withhold permission for

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proposed medical treatments or procedures based on full knowledge of relevant facts—is one of the foundations of modern medical ethics. This chapter analyzes informed consent as it is applied in its primary setting for competent adults, for incompetent adults, and for never competent children. I find informed consent to be a legal fiction in the latter two settings. The application of what is commonly called informed consent to neonatal male circumcision is analyzed in detail and shown to be the greatest legal fiction of all informed consent settings. When proxy consent is sought for neonatal circumcision, a thicket of conceptual, ethical, and practical difficulties are created. This legal fiction cloaks a usurpation of agency, thereby allowing supposedly respected ethical principles of autonomy and self-determination to be violated with little or no adverse consequences for the violators.

Informed consent is a legal doctrine that is only strictly applicable to a patient capable of consenting, that is, typically, a competent adult. In its intended setting of a competent adult patient, informed consent suffers from a number of theoretical and practical problems. Even basic information is often not effectively communicated to patients, a requirement to show actually damages effectively only protects reasonable patient consents, and a crucially important fourth element to informed consent—patient understanding—is omitted from most doctrinal formulations. Furthermore, informed consent is only applicable to incompetent adult patients via the legal fictions of proxy consent and substituted judgment, each of which introduces a host of distortions and discrepancies. In applying proxy permission to neonatal circumcision, we find ourselves confronted by a thicket of conceptual misapplications and theoretical distortions that stretches beyond the breaking point the ethical, moral, and human rights grounding of a parent's supposed medical permission for the procedure.

Schuck eloquently summarizes the somewhat unique power consent has in our culture:

> Consent is the master concept that defines the law of contracts in the United States. First, consent expresses the primacy of individualistic values in our culture…. Second, consent is instrumental to economic efficiency, a cherished value in American culture…. A third foundation for consent in American law more generally is our abiding, almost obsessive suspicion of state power (Schuck 1994 pp. 900–901).

Subject to certain exceptions—emergencies posing threats to life or danger of grievous bodily harm, self-defense, jostling in a crowd, and contact sports—a person who suffers a touching by another to which they did not consent is entitled to an action in battery. Since ancient times, consent has been the only defense to a cause of action for battery. In a medical context, since at least 1767, courts have agreed that liability for battery results from a completely unauthorized medical procedure or a procedure on a body part different from the one discussed with the patient.[1] Thus surgery is a technical battery that, regardless of the health-care provider's intentions, can be excused only when there is express or implied consent from the patient.[2] This is true even if the treatment proves to be beneficial or even necessary to preserve a

[1] Slater v. Baker and Stapleton, 95 Eng. Rep. 860 (1767).
[2] See Newmark v. Williams, 588 A.2d 1108, 1115–16 (Del. 1991).

patient's life.[3] A defendant who commits battery is liable for all consequences of his wrongful conduct, intended or not, and foreseeable or not.[4]

What liability exists if a procedure is consented to but the consent is not informed? For example, a procedure may be authorized but not properly explained so that the patient understands what he or she is agreeing to. In that event, battery seems not to provide the right analytical frame. According to Harrington, "Battery, with its connotations of violence and criminality, is seen as an inappropriately stigmatic label for doctors seeking in good faith to act in their patients' interests. Instead a duty of disclosure is imposed upon physicians, breach of which sounds in negligence. This requires that the doctor has been at fault by falling below the level of care expected of him by the law as a medical professional" (Harrington 1996, p. 352).

1.1.1 Changes in Doctor–Patient Relationship Usher in Informed Consent

Throughout the ages physicians believed that they, based on their training and expertise, were in the best position to make treatment decisions for their patients. This conviction inheres in the Hippocratic Oath, which does not mention the patient as a person whose ability and judgment deserve consideration. Indeed, in one of the few references to disclosure in the Hippocratic Corpus, physicians are admonished "to [conceal] most things from the patient…." Twenty-six centuries later, in the early 1950s the influential Harvard sociologist Talcott Parsons, who echoed physicians' views, stated that the physician's competence and specific judgments and measures cannot be competently judged by the layman and that the latter must take doctors' judgments and measures on 'authority' (Katz 1994, pp. 73–75).

The power imbalance between patients and doctors is clear. Jones notes, "Part of the imbalance between doctor and patient is due to the patient's lack of information, and, on one view, it is the function of the law to redress the imbalance by providing patients with the 'right' to be given that information, or perhaps more accurately imposing a duty on doctors to provide it" (Jones 1999, p. 129). A little over a half-century ago, American legal cases emerged to alter the relationship between patients and doctors by introduction of the informed consent doctrine.

1.1.2 Birth and Development of Informed Consent in Court Cases

Law, not medicine, drove change in the standards of communication between doctors and patients. In the US, as long ago as 1891, the United States Supreme Court recognized the right of all citizens to bodily integrity and self-determination. "No

[3] See Matter of Storar, 420 N.E.2d 64, 71 (N.Y. 1981).

[4] See Talmage v. Smith, 101 Mich. 370, 59 N.W. 656 (1894).

right is held more sacred, or is more carefully guarded by the common law, than the right of every individual to the possession and control of his own person free from all restraints or interference of others, unless by clear and unquestionable authority of law" (Feigenbaum 1992, p. 862).

Nearly a full century ago, in 1914, while still not requiring informed consent, Justice Cardozo famously proclaimed the importance of consent to medical treatment: "Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault for which he is liable in damages."[5]

In the US, the basis for the medical duty of *informed* consent first appeared in 1957 in the decision by the California Court of Appeal in *Salgo v. Leland Stanford, Jr, University Board of Trustees.* The court held that a physician violates a duty to his patient and subjects himself to liability if he withholds any facts that are necessary to form the basis of an intelligent consent by the patient to the proposed treatment.[6] According to Jay Katz, the new principle requiring doctors to share decision-making authority with their patients shocked the medical community and "constituted a radical break with the silence that had been the hallmark of physician-patient interactions throughout the ages" (Katz 1994, p. 72).

Continuing this trend in jurisprudence, *Canterbury v. Spence,* in 1972, held that any competent adult has a right to determine what shall be done with his or her own body, what we might today call a right to bodily integrity. The court held that genuine consent requires a choice that is properly informed. For the choice to be informed, there must be an opportunity to knowledgeably evaluate the alternatives and the risks entailed by each alternative. The court, presumably troubled by the concept of conferring liability simply for not being informed of an option, held that principles of self-determination permit liability only if nondisclosure would have affected the decision of a fictitious "reasonable patient."[7] The patient can only make a recovery if it can be shown that proper information would have produced a different decision, but not by the actual patient, but rather by a hypothetical reasonable patient. Some of the difficulties created by this analysis are discussed below.

In 1979, in *Scott v. Bradford*, the Oklahoma Supreme Court expanded on Canterbury by holding that a physician "has a duty to disclose to a patient all relevant material information his patient will need to make an informed decision on whether to consent to or reject physician's proposed treatment or surgery. This disclosure shall include alternatives to proposed treatment, and the risks of each course of action including those risks inherent in foregoing all treatment." Because of the critical interests at stake, consent must be "informed" in order to be valid: the individual must know to what he is consenting. If the physician has not given the patient all the information that the patient needs to make a knowledgeable

[5] Schloendorff v. Society of New York Hospital, 105 N.E. 92, 93 (N.Y. 1914).

[6] Salgo v. Leland Stanford Jr. University Board of Trustees, 154 Cal. App. 2d 560, 317 P.2d 170 (1957).

[7] Grounded in the ethical principle of respect.

decision regarding his medical care, any consent the patient gives is ineffectual.[8] Grounded in the ethical principle of respect for autonomy, informed consent protects the patient's rights to bodily integrity and self-determination, as well as promotes the patient's interest in rational decision-making (Annas 1977; Berg and Appelbaum 2001; Faden and Beauchamp 1986).

Unfortunately, as we will see, the ideal of informed consent is not always realized in clinical practice. Further, informed consent suffers from numerous shortcomings, both theoretical and practical, problems that exist even within its intended sphere of applicability to competent adults but which become even more intractable when attempts are made to apply informed consent to incompetent adults or to children.

1.2 How Informed Consent Plays Out with Competent Adults

According to Jackson, "Informed consent is commonly used as a shorthand for two distinct duties: the duty to obtain the patient's consent before treatment, and the duty to ensure that the patient has been properly informed about its risks and benefits" (Jackson 2006). Informed consent refers to a process of adequate *disclosure* of relevant information which may then be the basis for a decision to *voluntarily* give (or refuse) consent for medical treatment of a *competent* patient. Disclosure encompasses providing to the patient all information that is *material* to his or her decision regarding whether to agree to a proposed medical procedure including *alternatives* to the procedure. Voluntariness addresses the patient's ability to make health care choices free from manipulation or undue influence, which can include *timing, manner, or order* of disclosure designed to promote a particular decision by the patient. Competence refers to the patient's capacities to understand and process information and to reason about the consequences of possible medical courses of action. Competence relates to an often forgotten fourth element of informed consent—the patient's level of *understanding* of the information provided.

As we will see, even within the realm in which it is squarely applicable—competent adults—informed consent, while retaining some level of logical coherence, suffers from both conceptual and practical problems.

1.2.1 Disclosure

The physician's duty of disclosure arises from the patient's rights to autonomy and self-determination, which imply an entitlement to receive all relevant information prior to authorizing a procedure that otherwise would violate the person's human

[8] Scott v. Bradford, 1979 OK 165; 606 P.2d 554, 559 (1979).

rights and legal rights to privacy, autonomy, and bodily integrity. In addition to honoring the person's autonomy and self-determination, disclosure promotes a patient's ability to cope with the consequences—favorable or otherwise—of the selected procedure.

One widely noted study found that in practice "[o]nly 26 % of [consent] forms included all 4 basic elements" of disclosure (Bottrell et al. 2000, p.26). Similarly, Wu found that "clinicians infrequently communicate the four elements essential for informed consent "(Wu and Pearlman 1988, p. 12).

Numerous studies demonstrate that informed consent operationally fails to function as it is supposed to, even within its most fundamental context of competent adult patients. This breakdown occurs for a variety of reasons. First, physicians fail to satisfy the elements of informed consent. As summarized by Michael Jones, "[w]hatever the reason, many doctors are not good at communicating with patients and there are numerous studies in medical journals which demonstrate that in reality many if not most patients remain completely uninformed" (Jones 1999, p. 129). Moreover, doctors often do not disclose even the most obvious and crucial facts, such as major side effects of treatments (Bottrell et al. 2000, p. 26). One study found limited physician disclosure of side effects of nonsteroidal anti-inflammatory drugs other than epigastric discomfort (Katz et al. 1992, p. 1257).

Disclosure of adequate information is the first step in the informed consent process and review of the information disclosed is relatively tractable compared to less tangible issues such as voluntariness and competence. Accordingly, disclosure is often the primary feature of consent communication in the clinical setting.

On the other hand, courts often focus on disclosure at the expense of the other elements of the informed consent process, which contributes to what can be a counterproductive exercise of physicians disclosing all conceivably relevant information. Karako-Eyal summarizes the problems with this approach:

> First of all, piling vast amount of information onto patients detracts from their ability to understand the information given to them… Second, providing patients with information on *all* of the risks involved in the treatment, including rare risks, is likely to dissuade patients from obtaining needed medical treatment… Third, as the scope of the information given to patients increases, so does the amount of time devoted to the informed consent process and the costs involved therein (Karako-Eyal 2010, p. 20).

Materiality

Materiality as a criterion for disclosure addresses whether a patient would consider a given piece of information relevant to his or her process of evaluating the relative advantages and disadvantages of different treatment options. A physician has a duty to disclose all information that he or she knows—or *should* know—would be regarded as material by a reasonable person, which implies a duty of physicians to keep up to date with the relevant literature (Svoboda et al. 2000).

Naturally, there is a limit to how much and what kind of information medical professionals must provide. Even very slight risks generally must be disclosed to patients, particularly if the consequences may be severe. The High Court of Australia

ruled that a physician was negligent for not disclosing a 1 in 14,000 chance that an elective eye operation would leave a patient blind in that eye, even though the risk was slight. The rare complication occurred, and the doctor was found liable.[9]

The Importance of Alternatives

As part of the process of obtaining informed consent prior to a proposed procedure, physicians are required to give patients all reasonably available, relevant information regarding alternative treatments, including the option of doing nothing (Berg and Appelbaum 2001; Wear 1998). The patient should be given enough information about the nature of each therapeutic option, and its advantages and disadvantages, to make a valid choice between alternatives. Informing the patient about options allows him to make decisions by weighing the potential implications of each—both medically and in terms of quality of life issues—based on his personal values, tolerance for risk, life goals, and the like. Ethically, this promotes the patient's autonomy as well as his human right of self-determination by promoting an informed, meaningful decision. Legally, health professionals are liable if alternatives are not adequately disclosed as this failure mitigates any consent thereby obtained as not truly informed.

At least in theory, the alternative of doing nothing always exists. Accordingly, at least in a non-emergency situation, the patient should always be informed of the prognosis with no treatment. As one court's opinion put it, "How can a patient give an informed consent to treatment for a condition if the patient is not informed that the condition might resolve itself without any treatment at all?".[10]

Studies show that alternatives are not being properly disclosed. One study found, "When examined across all decision categories, few decisions (9.0 %) met criteria for completeness of informed decision making." Moreover, "there was seldom discussion of alternatives (5.5–29.5 %) (Braddock et al. 1999, pp. 2317–2318). Another set of researchers determined that while 52 % of physicians mentioned the possibility of alternatives to the procedure in general terms, only 2.3 % specifically described alternatives (Bottrell et al. 2000, p. 29).

1.2.2 Voluntariness

In addition to proper disclosure of material information by health professionals, a second requirement for an informed consent to a procedure is that the decision be made voluntarily. The decision must be freely and autonomously made, absent coercive or unduly manipulative forces. For example, medical personnel must abstain from distorting or omitting information to promote a desired patient choice. The ethical goal of autonomy is thereby safeguarded. On the other hand, coercion or manipulation may

[9] Rogers v. Whitaker, 175 C.L.R. 479, 489–491 (Austl. 1992).

[10] Wecker v. Amend, 918 P.2d 658, 661 (Ka. Ct. App. 1996).

by definition alter a patient's decision from what she would have chosen of her own accord. Consent under the influence of such forces is legally and ethically invalid. Even full disclosure does not mitigate the effects of coercion or manipulation.

Timing, Manner, Order

Besides bald coercion and direct manipulation of information, the *process* of informing may be carried out in a range of ways that may impinge on voluntariness by restricting the autonomy of patient participation. The power imbalance between doctor and patient creates a great danger of undue influence. A patient often is for practical purposes restricted to responding to treatment options presented by the physician. Patients are of course often ill and anxious at the time informed consent is sought, rendering them even more vulnerable to influence by medical professionals. Because of this inherent imbalance of power, the timing, manner and order in which physicians present information can persuade the patient to select the option favored by the physician. Physicians should be sensitive to the likelihood that patients may interpret a suggestion, or even the mere mention of an option, as a recommendation.

The timing of disclosure is important. With an elective procedure that can be performed at any time, a physician must provide a patient with full disclosure far in advance to allow the patient sufficient time to reflect on whether to consent to undergo the procedure.

Regarding manner of disclosure, studies on preferable disclosure formats have produced mixed and in some cases surprising results, adding another obstacle of a more practical sort to the theoretical difficulties we reviewed above. Earlier studies seemed to suggest that some form of written disclosure, either alone or in combination with verbal disclosure, imparts greater knowledge than verbal disclosure alone (Etchells et al. 1996). More recently, at least one study suggested the opposite, with a form seemingly interfering with retention. "[P]atients remembered less of the information concerning anesthetic risks discussed during the preoperative interview if they received a preprinted, risk-specific anesthesia consent form at the beginning of the interview" (Clark et al. 1991, p. 13). In an early study producing counterintuitive results, a shorter form (mean score of 67 %) promotes greater understanding than a medium length form (mean score of 45 %), which in turn promotes greater understanding than a long form (mean of 35 %) (Epstein and Lasagna 1969, p. 684).

1.2.3 Competence/Capacity

Competence or capacity, the third element needed for legally and ethically valid informed consent, refers to the patient's ability to understand information regarding treatment decisions and to appreciate the consequences of a decision. This element protects patients' well being by ensuring that they have the cognitive

capacities necessary to engage in rational decision-making. Accordingly, physicians must assess whether a patient is capable of both understanding the relevant medical information and making a rational decision based upon that information. While adults are presumed to be competent to give informed consent unless proven otherwise, parents are most often designated as surrogate decision makers for children. The same elements of competence, disclosure, voluntariness, and understanding are required for valid informed consent in the case of surrogates, as for informed consent by a competent patient for himself.

1.2.4 Understanding: The Forgotten Element

A fourth, usually omitted element is that in pursuing informed consent for medical treatment, a physician must provide the information in a manner conducive to a patient's *understanding* of the material. Without understanding, the patient is not in fact informed. Accordingly, she is unable to exercise her rights of self-determination and autonomy and to safeguard her own bodily integrity through an informed decision. Understanding is hard to determine empirically; legally, the predictable result becomes court cases fought over whether every possible complication was mentioned by the physician, often with no attention to the patient's actual comprehension of the material.

Numerous studies document the often strikingly low levels of patient comprehension. A 1988 study in Australia found that 77 % of patients said that they wanted more information about their treatment (Dunkelman 1979, p. 311). Of 100 patients having chemotherapy who were given a written information and consent form, 75 could not name any of their drugs, 26 did not know the goal of therapy and 17 remembered none of the four general side effects. In the author's terse appraisal, "Such forms may not satisfy the requirements of informed consent" (Olver et al. 1995). Robertson emphasizes that the "extent of the patient's comprehension of the disclosed information should… be a vital issue" (Robertson 1981, pp. 111–112). The exercise of informed consent becomes pointless regardless of information disclosed if the information is not understood.

1.2.5 Exceptions to Informed Consent with Competent Adults

Besides situations involving *incompetent* patients, there are several other legally accepted exceptions to the patient's right to informed consent. Several are based on the principle of beneficence and are applicable in cases where the best interests of the individual or society are deemed significant enough to take priority over the patient's right to self-determination. These exceptions include *public health emergencies*, such as when individuals with tuberculosis are legally required to be quarantined and treated, out of a need to promote public safety; and *medical*

emergencies, in which a delay in order to obtain informed consent would place the patient at imminent risk of death or significant harm. Another exception that is becoming a relic of the past is the "therapeutic privilege" of the physician to withhold disclosure when the disclosure itself is deemed unduly harmful. A competent patient may voluntarily waive his right to information and/or cede decision making to the physician or someone else, but it is not clear that this "waiver" provides the physician any protection from a negligence suit.[11]

1.2.6 Problems with Informed Consent for Competent Adults

In addition to the practical problems mentioned above, the dictates of informed consent are simply not followed uniformly enough. Braddock found that "the ethical model of informed decision making is not routinely applied in office practice… By the most minimal definition consistent with an ethical framework, decision making in clinical practice may fall short of a basic level of patient involvement in routine decisions" (Braddock 1999, p. 2319).

Moreover, informed consent suffers from at least two glaring conceptual problems evident even in its intended regime of competent adult patients. As decided in *Canterbury v. Spence*, a claimant must typically show actual damage based on reference to a reasonable patient. Yet the right of informed consent obviously cannot logically require a "reasonable" decision as the right then becomes an empty letter. "Physicians, bioethicists, or the state need not agree with the patient's choice, nor even judge the choice reasonable" (Cherry 2010, p. 790).

Perhaps the Oregon Court of Appeals best summed up the self-contradictions of this still reigning approach, in a leading case interpreting and, on this point, questioning *Canterbury v. Spence*: "We are aware of no other context in which it has been suggested that the jury should resolve a question of causation on the basis of a hypothetical effect that a hypothetical defendant's act is likely to have on a hypothetical plaintiff, rather than base its decision on whether the actual defendant's act was the cause of harm to the actual plaintiff."[12] The Oklahoma Supreme Court went even further, rejecting *Canterbury* on this point and eloquently noting what is lost to patients:

> The *Canterbury* view certainly severely limits the protection granted an injured patient. To the extent the plaintiff, given an adequate disclosure, would have declined the proposed treatment, and a reasonable person in similar circumstances would have consented, a patient's right of self-determination is *irrevocably lost.* This basic right to know and decide is the reason for the full-disclosure rule. Accordingly, we decline to jeopardize this right by the imposition of the "reasonable man" standard .[13]

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[11] Reibl v. Hughes, 114 D.L.R. 3d 1, 15–17 [1980].

[12] Arena v. Gingrich, 733 P.2d 75,76 (1987).

[13] Scott v. Bradford, 1979 OK 165; 606 P.2d 554, 559 (1979).

Nevertheless, this problem persists today as *Canterbury* and the contradictions pointed out in 1979 remain the law in most jurisdictions.

Maclean notes "the inconsistency between what the law claims to be the patient's right and what it is prepared to compensate. The law proclaims that the patient can make any decision regardless of reason. However, it is then only prepared to compensate those cases of a failure to disclose where claimants provide credible evidence that they would have made a different decision." To solve the conundrum, Maclean not unreasonably advocates "establishing a distinct liability for 'breach of consent to medical treatment'" (Maclean 2009).

Secondly, the important fourth element to informed consent—patient understanding—is omitted from most formulations of the doctrine, rendering it both legally and ethically invalid. As discussed above, numerous studies found that understanding is all too often absent from informed consent. Several authors conclude that informed consent seems primarily to be a legal self-protection exercise rather than a process genuinely designed to safeguard the patient's interests (Muss et al. 1979, p. 1556; Bottrell et al. 2000; Cassileth et al. 1980, p. 896).

1.2.7 Informed Consent and Non-therapeutic or Elective Surgery on Competent Adults

Elective surgery refers to surgery as a possible treatment option for non-emergent disease, in which there is not yet a medical consensus that surgery is the best course. Even with competent adults, the physician is under a stringent duty to guard against financial self-interest and to clarify the elective nature of the surgical route, while objectively presenting all reasonable alternatives and their likely benefits and burdens. Because of both the lack of clarity as to optimum treatment and also the longer time horizon for deliberation, Lustig and Scardino have argued that elective surgery demands a more extensive informed consent dialogue over a period of time. Such a process is more likely to give the patient an opportunity to fully absorb and meditate on all options, so as to optimize his autonomy and self-determination in reaching a plan that is best for his unique situation (Lustig and Scardino 1998).

Elective procedures may be subject to a stricter informed consent requirement than medically indicated procedures. A number of legal and medical scholars have suggested that the duty of care for disclosure should be higher when the procedure is elective (Berry 2005; Haberfield 1997; Schuck 1994). The usual practice of informed consent and disclosure of treatment alternatives is based on the premise that a medical problem exists that requires therapeutic intervention of some type for relief or correction of the problem. Somerville states, "a very full disclosure is needed when non-therapeutic medical intervention is involved," justifying this assertion on the grounds of giving patients a chance to more carefully consider deciding *against* procedures that have no therapeutic function (Somerville 1981).

1.3 Substituted Judgment for Incompetent Adults

Application of the doctrine of informed consent to incompetent adults requires use of a legal fiction—most commonly that of "substituted judgment"—as incompetents by definition cannot give informed consent. Under substituted judgment, a surrogate for an incompetent adult patient, typically a relative, is legally *permitted* to make decisions on behalf of the patient in furtherance of the rights *of the patient*. Surrogates are under a legal obligation to decide not on the basis of how *they* want the patient to be treated, but rather on the basis of how *the patient* would choose to be treated if he or she were capable of choosing. The more a surrogate seems influenced in her decision-making by his or her personal values and preferences, the less willing a physician should be to accept the surrogate's permission for a procedure. Substituted judgment typically requires the substitute decision-makers to present clear and convincing evidence as to the wishes of the patient before he or she became incompetent.[14]

Legal use of the substituted judgment doctrine dates to early nineteenth-century England, where it was initially invoked as a legal fiction allowing courts to distribute parts of a "lunatic's" or "idiot's" estate to relatives that were not owed any legal duty of support.[15] *In re Quinlan,* the first of the two US cases that are most identified with the doctrine, involved a once-competent woman in a persistent vegetative state. The New Jersey Supreme Court invoked the principle to reject a claim by the woman's parents that the hospital must withdraw life support because the claim was inconsistent with the parents' religious values.[16] In *Superintendent of Belchertown State School v. Saikewicz,* treatment for a severely retarded man with leukemia was withheld on the grounds that he himself would have refused treatment were he competent, but, at the same time, aware of his perpetual and irreversible incompetence.[17] Such a conclusion had no evidence to support it and again shows the tendency of paradoxes and inconsistencies to mount in applications of informed consent.

Even Judge Paul Liacos, the author of the opinion, admitted that attempting to implement substituted judgment in such a case "involves a legal fiction to some extent" (Liacos 1989). When no evidence of the patient's preferences or values is available, or when the patient has never been competent, surrogate decision-making often reverts to the *best interests* standard. Under the best interests standard, surrogates are directed to make necessary decisions based on what in their estimation would produce the highest net benefit to the incompetent patient, by careful and informed weighing of the patient's interests against the risks and costs of available treatment options. However, the ethical principle of best interests is problematic because it relies on the decision-maker referring to his or her own conception of quality of life, and then being able to appropriately apply this

[14] See Cruzan v. Director, Mo. Dept. of Health, 497 U.S. 261, 284–286 (1990).

[15] Ex Parte Whitbread in the Matter of Hinde, a Lunatic, 35 Eng. Rep. 878, 878 (Ch. 1816).

[16] In re Quinlan, 355 A.2d 647, 661-62 (N.J. 1976).

[17] Superintendent of Belchertown v. Saikewicz, 370 N.E.2d 417, 421, 431 (Mass. 1977).

conception to the patient and his future life. Because it is not their own bodies that are affected, there may be more of a tendency for surrogates to overlook or minimize harms that may result from decisions made for others.

An alternative approach that might be better founded ethically would follow Kant and Rawls in treating the infant as an end unto himself and never a means to an end. Under this approach, consideration would be given to the infant's position and the inherent value of his life and self-definition and using universal moral principles to guide decision-making in a manner more analogous to substituted judgment (Kant 1956; Rawls 1971, 1993).

1.3.1 Problems with Substituted Judgment for Incompetent Adults

One problem with substituted judgment is that it requires the acceptance of an oxymoron—that one's autonomy can be exercised by another. The notion that a court or any third person can decide for the incompetent person under a theory of substituted judgment denies the very autonomy from which the doctrine takes its life. "[T]hat decisions concerning a particular person's fate are better made *for* him than *by* him, because others wiser than he are more keenly aware of his best interests than he can be—conflicts with the notion of a right of self-determination."

A practical problem with decisions made by surrogates is that there is considerable evidence to show that surrogates do not always make choices that conform to what their wards would actually have chosen for themselves. A review of sixteen studies of still-competent patients and their designated surrogates found that nearly one third of the surrogates failed to correctly predict the treatment preferences of their designated wards in hypothetical end-of-life treatment decision scenarios (Shalowitz et al. 2006). An even greater lack of accuracy in surrogate decision-making—an abysmal 34 % agreement—has been found in research on hypothetical situations concerning elective surgery (Mantravadi et al. 2007).

Suhl found "patient surrogates guessed no better than would have been expected from random chance alone. This was true despite a generally long and close relationship between the patient and the surrogate, and the belief by virtually all pairs that the surrogate knew the patient's wishes" (Suhl 1994). Understandably, one such study concluded, "In light of these findings, it is apparent that this substituted judgment standard, intended to allow for an incompetent patient's right to autonomy, should be re-evaluated" (Seckler et al. 1991, p. 96).

1.4 Proxy Permission for Never Competent Children

Proxy permission for medical procedures on never competent children—most commonly provided by parents or other guardians—is itself a legal fiction but is at least linguistically accurate. By contrast, the widespread terminology "informed

consent" in relation to never competent children is incorrect and misleading. Parents cannot "consent" based on an examination of their own values and preferences, as they would for a procedure on themselves, but rather can merely, as guardians, grant permission *on behalf of the child*, and only for procedures that are necessary to ensure the child's well-being (Committee on Bioethics 1995).

While one might assume that the grounding of informed consent in principles of autonomy and self-determination is inapplicable to incompetent children, the principle of autonomy should help guide parental decision-making for children. Citing Joel Feinberg's argument for the child's "right to an open future" (Feinberg 2007), Berg et al. have written:

> It may seem strange to speak of promoting the autonomy of incompetent patients. Yet some patients are only temporarily incompetent and non-autonomous, as when they are briefly unconscious or are infants. These patients will regain consciousness or mature; decisions made on their behalf should, therefore, safeguard their future autonomy and their opportunities to make future autonomous decisions. For this reason, for example, parents generally may not elect to sterilize their children; to do so would infringe on the future reproductive autonomy of their children (Berg and Appelbaum 2001, p. 94).

The British Medical Association (BMA) agrees on the need for "prioritising of options which maximize the patient's future opportunities and choices" (Medical Ethics Committee, British Medical Association 2006, p. 4).

A child's parents possess temporary authority to make health care decisions on behalf of their children, where the procedure is in the best interests of a child, and the child is incapable of consenting on his own behalf (Feigenbaum 1992, pp. 852, 875). Courts have recognized that parents do not possess an unrestricted authority to make decisions on behalf of their children. Parents are not permitted to make "martyrs" of their children.[18] Accordingly, the state can interfere via the *parens patriae* (parent of the nation) doctrine when serious harm or death to the child is likely to result from the parents' acts or omissions, which can create an "irreconcilable tension between child protection and parental deference" (Rosato 2000, p. 10).

1.4.1 Parent and Physician Duties in Proxy Permission for Never Competent Children

While the analysis of parental proxy consent for children is sometimes carried out under the principle of "substituted judgment," it is more commonly done as a best interests analysis. The physician's professional and legal duties in this context are at least as stringent as in the case of an autonomous adult. Physicians also have a duty to ensure that the surrogate is capable of understanding the information provided and of fully appreciating the consequences of a decision at the moment of decision-making. Likewise, physicians are obliged not to manipulate the surrogate

[18] Prince v. Massachusetts, 321 U.S. 158 (1944).

by presenting the information in a manner designed to secure permission, rather than facilitating an objective evaluation of the risks and benefits of the procedure. It is improper for a physician to suggest a procedure that is not medically indicated to parents who have not inquired about it. In addition to these requirements, which also arise in securing informed consent from a competent patient, a physician seeking permission for a surgical procedure on an incompetent adult must ensure that the substitute decision-maker is not acting out of self-interest but rather is deciding on the basis of what is best for the patient.

Parents, like substitute decision-makers for incompetent adult patients, should be viewed as agents for their never competent children, required to make decisions regarding medical interventions for their children in a manner consistent with their children's best interests. Surrogates should strive to maximize benefits while minimizing harms to the child patient. Factors to be considered in determining a child's best interests should include: the balance of the harms and benefits of treatment options; the evidence on long- and short-term outcomes of treatment options; long-term implications for the child's suffering and quality of life; how likely the proposed treatment is to improve or prevent deterioration of the child's condition; the child's chances of survival; and whether the proposed treatment is the least restrictive and least intrusive way to obtain the hoped-for benefits (Longley 2009).

Medical professionals owe a duty to their minor patients to assist parents in making decisions that conform to that standard. According to the American Academy of Pediatrics Committee on Bioethics, parental permission for medical intervention is authorized only in situations of clear and immediate medical necessity, such as disease, trauma, or deformity. Where parents request a procedure that is *not* medically indicated, courts have taken an even more child-protective stance than applies to medically justified procedures, requiring strong evidence that the procedure is in the patient-child's interests and does not entail parents inappropriately injecting their own preferences into the decision-making process. For example, even if a kidney transplant would save the life of a close relative, the decision must be made based exclusively on the patient's own interests.[19] The benefits of the proposed procedure must clearly outweigh short- and long-term disadvantages, and spiritual costs and benefits may not be incorporated into this analysis. The AAP Committee directs that for non-essential treatments, particularly those (such as neonatal circumcision) that can be deferred without loss of efficacy, the physician and family wait until the child's consent can be obtained (American Academy of Pediatrics Committee on Bioethics 1995, pp. 314–316). The AAP Committee and the United Kingdom Department of Health guidelines both stress that providers have legal and ethical duties to their child patients to render competent medical care based on what the patient needs, not what someone else expresses (Committee on Bioethics 1995, p. 315; Department of Health 1991).

While in certain circumstances patients may themselves be able to provide legally valid consent to prophylactic removal of their own healthy tissue, parents

[19] See Strunk v. Strunk, 445 S.W.2d 145, 148–149 (Ky. 1969); Hart v. Brown, 289 A.2d 386, 387-88 (Conn. Super. Ct. 1972).

can never grant permission for prophylactic removal of healthy tissue from their children and can only consent to medically necessary procedures. Because the foreskin is a normal, functional anatomical structure, and because routine neonatal circumcision has no recognized therapeutic benefit, parental consent for "routine" circumcision is invalid.

1.5 Proxy Permission for Neonatal Circumcision on Never Competent Baby Boys

We have seen that informed consent fails to protect patient's rights properly even for competent adults, and it fares worse within the realm of substituted judgment for incompetent adults. When proxy consent is to be granted to authorize neonatal circumcision on never competent baby boys, a plethora of interconnected conceptual, ethical, and practical problems arise. Proxy permission for an elective procedure that lacks medical indication conceals a usurpation of the child's agency, in violation of the ethical principles of autonomy and self-determination. Accordingly, the doctrine of proxy consent by parents for neonatal circumcision of their infants proves to be the most distorted legal fiction of all, ethically and legally unable to sustain its claims to legal authorization, medical authorization, and compliance with human rights.

We as a society thereby conceal from ourselves our failure to adequately protect the human rights and ethical entitlements of human dignity and autonomy whose importance we profess to recognize.

1.5.1 Background of Proxy Permission for Neonatal Circumcision

While the other English-speaking countries have since virtually abandoned neonatal circumcision, the United States has seen a slower but still precipitous drop in circumcision rates from a peak of approximately 90 % in the 1960s to—according to the Centers for Disease Control and Prevention (CDC)—33 % in hospital in 2009 (El Bcheraoui 2010). Longley notes: (colon) "it is interesting that the beginning of the shift coincided with the incorporation of informed consent into modern medical practice" (Longley 2009, p. 2).

Proxy consent stressed the ethical justification of parental permission for neonatal circumcision, in that information must be provided in a way that allows parents to make an autonomous decision, yet it is the child who is the patient and whose body and life will be affected by the decision. Indeed, because of this quandary, some authors have argued that non-therapeutic neonatal circumcision does not meet the legal criteria for valid parental consent (American Academy of Pediatrics Committee on Bioethics 1995; Canadian Paediatric Society Bioethics Committee 2004; Svoboda et al. 2000).

1.5.2 Medicalization Helps Justify and Perpetuate Neonatal Circumcision

A sleight of hand is lurking that is usually tacitly glossed over but whose significance should not be missed. As proxy consent to a procedure lacking medical justification is not possible, proxy consent is only relevant to circumcision based on its questionable status as an ostensibly medical procedure. No reputable medical organization maintains that neonatal circumcision has medical benefits justifying its performance (Circumcision Information and Resource Pages 2011). Circumcision has joined other originally non-medical practices that are now conceptualized as medical—for example, dying, alcoholism, drug addiction, and erectile difficulties (Carpenter 2010). Circumcision has followed a trajectory from being conceptualized as a religious procedure to a medical procedure. This explains why informed consent is applied to it. Under a pretense of legal authorization and compliance with human rights, we thereby mask our failure to properly protect human dignity and self-determination. Circumcision entails one further pretense that should not be overlooked—a suggestion of medical authorization where in fact none exists.

1.5.3 Disclosure: Circumcision

"[P]arental decisions to have infant sons circumcised are not based on adequate information" (McDermott et al 1982, p. 132). If doctors don't know this information themselves, they can't carry out their duties to inform their patients. One study found physicians' own knowledge regarding normal foreskin anatomy to be inadequate (Stein et al. 1982, p. 47). Predictably, this lack of information leads to harm to the doctors' child patients. Two studies completed in 1996 and 2001 respectively found that 25 and 37 % of mothers believed they had not been given enough information to make a meaningful decision regarding circumcision (Ciesielski-Carlucci et al. 1996; Adler et al. 2001). To further complicate matters, information does not always necessarily even help. Parents in one group that was provided with a written statement of the advantages and disadvantages of circumcision actually were slightly more likely (98–96 %) to authorize the circumcision of their newborn sons (Herrera et al. 1982).

Materiality: Neonatal Circumcision

Physicians who perform circumcisions have a legal and ethical duty to their infant patients to obtain and provide all available medical information to the patients' parents. This includes information about the nature and function of the foreskin, the pain that its removal causes even with pain relief, the risks of any pain relief, the risk of complications, any possible medical costs caused by its amputation,

and a full examination of the alternative of not circumcising. Doctors rarely fulfill this duty, (Christensen-Szalanski et al. 1987; Fletcher 1999; Longley 2009, pp. 237–239) and thereby violate their ethical and legal obligations as well as the legal rights and human rights of their patients.

Because healthy, functional tissue is removed with every circumcision, the complication rate of circumcision arguably is 100 % (Svoboda et al. 2000). The risk of additional immediate complication is between 2 and 10 % (Williams and Kapila 1993). There is an additional 5–10 % likelihood of a later physical complication (Van Howe 1997a; Patel 1966; Van Howe 2006). The risk of a potentially lifelong psychological and/or sexual complication also exists (Boyle et al. 2002). A risk of death also exists, and sadly well over one hundred iatrogenic deaths from neonatal circumcision occur annually in the US (Bollinger 2010). Physicians are clearly obligated to make parents aware of these complication rates and the nature of the harms that might befall their son. No significant medical benefit has clearly been demonstrated to result from routine neonatal circumcision, and physicians have a duty to inform parents of that fact.

Importance of Alternatives: Circumcision

In the case of circumcision, alternatives that should be disclosed include type of pain relief if any, and the surgical method. However, the most significant alternative is simply that of doing nothing and allowing the boy to grow up with his natural genitals intact. One much cited study of circumcision disclosure found that doctors failed to discuss the alternatives, including no treatment (Ciesielski-Carlucci et al. 1996). Longley documents that the needed information on circumcision should be demystifying, normalizing, should give value, and should support (Longley 2009, pp. 237–239). "It is thus apparent that if parents, as guardians, consent to have their male neonates circumcised without a clear discussion of alternatives offered by the physician or hospital staff, and if at a later date they find the procedure to have been unnecessary or find that complications develop as a result of the procedure, they may successfully make the health-care providers liable for having failed to provide alternatives to the procedure" (McDermott et al. 1982, p. 135). Longley found that in North America, most handouts provided pursuant to the informed consent process did not provide adequate information on the option of *not* circumcising (Longley 2009, pp. 219–220). Accordingly, providers in the US and Canada fail to satisfy the important principle of providing adequate disclosure of viable alternatives.

1.5.4 Voluntariness: Neonatal Circumcision

Longley points out the wide range of forces that can distort parental decision-making, including unfamiliarity with the intact penis, widespread myths and misinformation about the foreskin, and social pressures including the (fading) notion of circumcision as a social norm. Parents are also subject to undue influence from

power imbalances in the relationship between patients and health care providers; a simple question from a physician may be interpreted by parents as a recommendation for circumcision (Longley 2009, pp. 234–236). Accordingly, parental decisions about circumcision made under these conditions are unlikely to be either adequately informed or truly voluntary.

The voluntariness requirement demands that physicians provide information regarding circumcision to parents in an unbiased fashion well in advance of the birth and certainly that physicians do not solicit the procedure. Given the procedure's elective and non-therapeutic nature, a physician should assume, unless the parents indicate otherwise, that the baby is not to be circumcised. Unfortunately, current practice appears inconsistent with the voluntariness requirement. Even today, it is routine in the United States to ask a woman during one of the initial prenatal visits whether she desires circumcision for her child if it is a boy (Van Howe 2011). It is a subtle form of coercion; offering circumcision to a mother can easily be interpreted as a recommendation.

Timing, Manner, Order: Neonatal Circumcision

Timing, manner, and order of presentation of informed consent for circumcision can all be improved. Sixty-three percent of the parents in one study faced the issue for the first time at birth or shortly before, and they were forced to make a fast decision, which the authors found unfair for the parents and babies (Herrera and Trouern-Trend 1979, p. 1070). Regarding timing in circumcision informed consent, Van Howe observes, "Ethically it is probably best to wait for *parents* to initiate the circumcision discussion *before* dispensing information" (Van Howe 1997b, pp. 88–89).

In circumstances where a child's best interests are unclear, the Canadian Paediatric Society recommends that "when it is possible to defer or delay acute treatment, such a delay is encouraged while further information is gathered to clarify the issues" (Canadian Paediatric Society Bioethics Committee 2004, p. 100).

Even more troubling is the fact—still common today—of parents being presented with the circumcision question for the first time when a mother is in labor at a hospital.[20] Pediatric urologist George Kaplan notes what he considers the "inexcusable" fact that "all too often the consent to circumcise is included in a sheaf of papers that the mother signs hurriedly on her way to the delivery room. No discussion has been held regarding the merits of the procedure or of the inherent risks" (Kaplan 1977). Similarly, Ciesielski-Carlucci et al. found:

> Of the providers who perform circumcision, 22 % do not routinely provide care during the prenatal period. Of those who perform circumcisions and provide prenatal care, 26 % do not discuss circumcision prior to delivery. That is, nearly half of the providers who perform circumcisions do not discuss the medical pros and cons of circumcision with mothers prior to delivery (Ciesielski-Carlucci et al. 1996, p. 231).

[20] Private communications on July 12, 2011 with Robert S. Van Howe, MD, Marilyn Milos, and Amber Craig.

Raising the circumcision issue for the first time upon the mother's arrival at the hospital to give birth amounts to manipulation and coercion. Because the physician and the hospital benefit financially from the parent's decision, such a practice raises grave concerns about unethical profiteering.

The AAP Committee on Bioethics sensibly recommends delaying elective, cosmetic surgery until a child is old enough to give consent, and this would apply to circumcision (American Academy of Pediatrics Committee on Bioethics 1995, pp. 315, 316–317). The Australian Association of Pediatric Surgeons has taken this position specifically with respect to circumcision (Leditschke 1996). Because no sufficient reasons exist for not deferring the procedure, ethically and legally it *must* be deferred, given the harm caused by the procedure and the probability that as an adult the patient will most likely not desire it.

Regarding the manner of presentation of information, Longley showed that North American sources—but not sources from Australia or New Zealand—ignored the benefits of an intact penis or problematized the intact penis. Accordingly, providers in the US and Canada framed information so as to promote circumcision and so as to render unattractive the option of keeping the baby boy genitally intact (Longley 2009, pp. 219–220). Clearly this did not honor their obligations under principles of informed consent.

1.5.5 Competence/Capacity of Proxy Agents: Neonatal Circumcision

Medical personnel have a duty to the newborn child to ensure that parental surrogates have the capacity to make a rational, reflective decision about circumcision. They should fully disclose all relevant information about the procedure well in advance of the birth, and then evaluate whether the parents understood the information. If the parents do not appear to understand, the physician should attempt to convey the information in another way that is clearer to the parents. At least one scholar has contended that parents are less rational in medical decisions concerning their children than they are in medical decisions concerning themselves (Alderson 1993). Medical personnel may therefore have a heightened duty when dealing with parental surrogates to ensure the surrogate is capable of making a rational decision on behalf of the infant patient.

1.5.6 Understanding: The Forgotten Element Neonatal Circumcision

Studies show that risks of circumcision are inadequately disclosed (Christensen-Szalanski et al. 1987; Fletcher 1999). A 1979 study found that "80 % of mothers stated that the risks of circumcision had not been explained to them" (Lovell

and Cox 1979, p. 811). Fully 25 % of mothers consenting to circumcision of their newborns believed there were no risks (Ciesielski-Carlucci et al. 1996, p. 233).

Care providers presumably avoid discussing the pain with parents because they fear it will be disturbing for the parents. But it *should be* disturbing, and physicians owe a duty to the infant patient to make his parents aware of this disquieting aspect of circumcision. They owe no duty to parents to make them feel better about granting permission for an unnecessary surgery.

1.5.7 Proxy Consent to Neonatal Circumcision: Conceptual Problems

The conceptual, ethical, and practical problems that crop up with "proxy consent" for neonatal circumcision underscore the difficulties that can arise from invocation of legal fictions, which by definition require fitting a fact situation into a legal analysis that is not designed to accommodate it. The AAP Committee evidently acknowledges this as its statement says the concept of "informed consent" does not apply to infant circumcision, because only a competent person can give consent (informed or otherwise) and an infant clearly is not competent. One commentator trenchantly observes, "The current inability of the medical community to differentiate between truly medically-necessary surgery and surgery performed for social and psychological reasons renders even fully-informed parents unable to consent to irreversible and unnecessary cosmetic genital surgery" (Lareau 2003, p. 151).

1.5.8 Proxy Consent to Neonatal Circumcision: Ethical Problems

In regard to circumcision, the BMA specifically states that "parents must explain and justify requests for circumcision, in terms of the child's interests" (Medical Ethics Committee, British Medical Association 2006, p. 4). While acknowledging the strong legal presumption against intervention into parental decision-making, various authors and professional organizations have voiced concerns about the ethical issues raised by pediatric proxy consent (American Academy of Pediatrics Committee on Bioethics 1995; Canadian Paediatric Society Bioethics Committee 2004; Svoboda et al. 2000).

The elective and non-therapeutic nature of neonatal circumcision, and the fact that it is undertaken by parental proxy consent, ethically requires a more stringent standard of information-giving than in other medical decision-making situations. Across the English-speaking world, the very validity of parental consent for neonatal circumcision is dubious. Bouclin finds that Canadian legal precedent limits parental authority to consent to "therapeutic" treatment only, or in situations of "imminent and serious danger requiring immediate treatment" (Bouclin 2005,

p. 214). The same principle applies in the US (Pappworth 1967). Recently, in Australia, the Tasmania Law Reform Institute has concluded that "there is uncertainty as to whether the consent of a parent for the circumcision of their child is sufficient to allow a circumciser to legally perform the procedure" (Marshall 2009). British pediatrician Jones argues that parental authority to consent to treatment is invalid "if it is not possible to demonstrate personal benefit to the child, or that the public interest is in any way served" (Jones 2000).

As an irreversible and medically unnecessary amputation that alters not only the appearance but also the function of the penis, neonatal circumcision can be seen as infringing on the future autonomy of the child to make his own decisions about how much of his natural penis he prefers to have. The approach that is most respectful of the child's future autonomy is to let the child be the definer of his own best interests, leaving the decision for him to make when he is old enough to give his own informed consent.

If the ultimate goal of medical decision-making for an incompetent person is to determine what the patient would decide for himself, if able, the best evidence may be what similarly situated competent persons actually decide for themselves. Only 1 in 200 intact males choose to have the surgery performed later in life, suggesting that the overwhelming majority believe that the risks and sequelae of becoming circumcised outweigh any supposed benefits (International Coalition for Genital Integrity 2011). Doctors should heed the AAP Committee's recommendation that the decision be deferred until the child can decide for himself whether to grant consent (Moore 1995, p. 320).

1.5.9 Proxy Consent to Neonatal Circumcision: Practical Problems and Considerations

Several practical problems with ethically obtaining proxy consent to circumcision are evident from experimental results. Physician under-reporting of risks and exaggeration of benefits seems to be the rule rather than the exception. Strong evidence suggests that a graphic depiction of the procedure—either a picture or a video—would be of significant help in educating parents about neonatal circumcision, and yet this is almost never done.

With respect to the risk of complications and the supposed medical benefits associated with circumcision, studies reveal that physicians under-report the risks and exaggerate the supposed benefits. A 1987 study found that physicians routinely inform parents about only three of the many possible complications of circumcision—namely, bleeding, infection, and pain (Christensen-Szalanski et al. 1987). Fletcher also found that bleeding, infection, and pain were the only complications to be discussed more than half of the time (Fletcher 1999). This is far below the standard level of disclosure for other surgeries, whether medically indicated or cosmetic. In circumcisions, the "principles of informed consent are often violated" (Ciesielski-Carlucci et al. 1996, p. 233).

We have already seen that presenting parents with video or pictorial images of the procedure helped inform parents of what circumcision entails. Yet this is almost never done. In 1980, one physician noted that use of printed educational materials clearly presenting advantages and disadvantages of circumcision led to a 30 % reduction in the neonatal circumcision rate (Gorske 1980). Solomon persuasively argues:

> parents have the right to see a video of a circumcision, if not at least a picture of a child restrained and being circumcised…. [B]ased on the fact that people's perception of what a circumcision is differs so radically from what actually happens during a circumcision, doctors are under an obligation to show parents a video, or if not, at least a photograph, of a baby being circumcised (Solomon 2007–2008, pp. 236, 238).

Seven studies have been performed to determine the effect of different informed consent procedures for neonatal circumcision such as verbal repetition of written disclosures, five of which found no difference in circumcision rates between the experimental and control groups (Binner et al. 2002; Christensen-Szalanski et al. 1987; Herrera et al. 1982; Maisels et al. 1983). This was attributed to the strength of social pressures, though obviously the importance of that factor has waned or even flipped now that in-hospital rates have—according to the CDC–declined to one in three nationwide (El Bcheraoui et al. 2010). Two of the seven studies found that circumcision rates were reduced in the group subject to an educational intervention. Rand et al. employed an experimental group comprised of obstetric patients who were given an accurate oral summary of risks as well as (supposed) advantages of circumcision. A substantial number of group members (28 % compared to 5.6 % of the control group) elected to keep their baby intact, and many of these parents had previously favored the procedure. The authors concluded that mothers who request circumcision do so based on inadequate medical information or strong social pressure (Rand et al. 1983, pp. 66, 64). Similarly, Enzenauer et al. found that the rate of circumcision in the experimental group dropped from the pre-study rate of over 90 % to about 70 % during the six-month intervention period. This study found that videotape counseling modestly reduced parental permission for circumcision from 75.9 to 70.5 % when compared with standard oral counseling (Enzenauer et al. 1986, p. 718). A factor that differentiates these two studies from the other five is that visual representations, either pictures or video, were employed to give parents an idea of what the procedure entailed.

1.5.10 Proxy Consent to Neonatal Circumcision as a Non-therapeutic, Elective Procedure

Because the foreskin is a normal, functional anatomical structure, and because routine neonatal circumcision has no recognized therapeutic benefit, parental consent for "routine" circumcision is invalid. Courts have uniformly held that surgical removal of any normal, healthy body part is not "treatment" and thus parental "consent" for such a procedure is invalid (Van Howe 1997b).

As mentioned above, the AAP Committee found that the concept of "informed consent" does not apply to infant circumcision. For the same reason, "patient assent" does not apply. Finally, the concept of "informed parental permission" cannot apply to infant circumcision because it only allows for medical interventions in situations of clear and immediate medical necessity, such as disease, trauma, or deformity.

Since neonatal circumcision is categorized as an elective procedure, we have already seen that a higher standard for informational disclosure is expected. When the procedure is, moreover, understood to be non-therapeutic, additional disclosure expectations are overlaid on this already elevated standard. The world's major medical organizations, having reviewed the evidence on the possible medical merit of neonatal circumcision acknowledge this fact, variously describing it as "non-therapeutic", (Council on Scientific Affairs, American Medical Association 1999) as lacking health benefits that justify its performance (Medical Ethics Committee, British Medical Association 2006) or likening it to a "cosmetic" procedure[21] done primarily for appearance rather than for health reasons.

According to bioethicist Somerville, the non-therapeutic nature of the procedure must be carefully made clear to the patient, particularly because "patients tend to identify physicians with therapy, and find it hard to believe that a physician would carry out a non-therapeutic procedure on them, even when they are expressly informed of this fact" (Somerville 1981). Moreover, the disclosure expectations generated by the non-therapeutic nature of neonatal circumcision are compounded to an additional degree by the fact that consent is provided by a proxy.

1.6 Conclusion

We have seen that while informed consent manages a degree of logical coherence when applied to competent adults, it fails to protect relevant concerns when applied by proxy to incompetent adults. This turns out to be more problematic when proxy consent is applied to never competent children for neonatal circumcision, which generates a hornet's nest of conceptual, ethical, and practical problems. Agency is thereby usurped, and ethical principles are violated without consequence to the violator. Physicians should approach decision-making on behalf of a newborn with the greatest caution and with a strong presumption against intrusive procedures. Amputating a highly sensitive and functional part of the body is extremely intrusive and should be undertaken only in situations of urgent necessity. Neonatal circumcision as it is routinely performed in this country clearly does not satisfy this criterion. It is therefore unethical and unlawful.

Infants do not have the capacity to give consent to any aspect of their medical care. Physicians may only obtain legally valid permission from parents to perform procedures on their incompetent children, provided full disclosure of all material

[21] American Academy of Family Physicians 2002.

information is made to parents who are able to understand the information and to appreciate the consequences of their decision, and provided that the parents are able to decide whether to grant their permission free from any manipulation or undue influence. Moreover, the only interventions for which parents may grant their permission are those conferring benefits that clearly outweigh the short- and long-term costs for the infant patient.

Because parents lack the power to give permission for prophylactic amputation of healthy tissue from their children, no parental permission for the procedure should be effective. Moreover, even if it were permissible for physicians to give effect to parental permission for circumcision, physicians would be under a stringent obligation to their infant patients to ensure that any such permission is informed—voluntarily given based upon competent review of all relevant information. Available evidence suggests that physicians today routinely fail to fulfill this duty. In doing so, they discredit their profession and expose themselves to legal liability. Video or at minimum photographs of a procedure should be routinely employed to educate parents as to the reality of the procedure.

The legal fiction of proxy consent to neonatal circumcision has not been directly considered by the courts. However, circumcision has gradually but steadily been falling out of favor in the past few decades, to the point where today more than two out of three boys leave the hospital intact. As the balance of public opinion shifts to opposing the practice, the legal system will become more accepting of lawsuits to protect baby boys. Consequently, the legal system will no longer be able to ignore the conflict between this practice and the legal and ethical duties of medical professionals relating to informed consent. The legal fiction of informed consent as applied to never competent newborns will crumble and genuine protection of the child's human rights, coupled with meaningful observation by practitioners of ethical principles of autonomy and self-determination, will become obligatory. Pretenses of legal and medical authorization and compliance with human rights and ethical requirements will dissolve forever.

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