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Infant Care Review Committees: Their Moral Responsibilities

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The moral duties of infant care review committees has become a widely discussed issue in the past few months among physicians, ethicists and legal scholars. It now appears as if these committees will come to have a great deal of responsibility over the care and treatment of handicapped newborns, and it is necessary to outline their moral duties in this role. Recently, very broad, formal, procedural guidelines for their proceedings have been suggested by other authors. In this paper, I wish to present a fuller account of what is morally required of these committees.

Ethics committees had their beginning in the decision rendered by the court in the *Matter of Karen Quinlan*.¹ In this decision, the court urged health care professionals, physicians and families to consult with ethics committees in difficult cases so that there could be full, free and open discussion of treatment issues. This proposal was not generally heeded by medical professionals or parents, largely because most seemed to want to preserve the traditional prerogatives reserved to them. As a result, few institutions established ethics committees after the *Quinlan* decision? In the years that followed this decision, only Catholic hospitals established ethics committees in large numbers.

Infant care review committees received their major impetus from the infamous Bloomington Baby Doe case for, in response to the death of that baby, the Department of Health and Human Services issued regulations to prevent the denial of care and medical treatments to handicapped children for the sole reason that they were handicapped. These regulations were based on section 504 of the Rehabilitation Act of 1973 and these regulations implied that:

No otherwise qualified handicapped individual . . . shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.⁴

Federal hotlines were initiated for the reporting of possible violations of this regulation, and many medical associations immediately protested these rules. Through a long series of negotiations, HHS accepted the legitimacy of infant care review committees when they were used in conjunction with federal hotlines.⁵ The widespread acceptance of these committees, along with the growing awareness that the traditional parent-physician-patient relationship was no longer adequate, spurred the present interest in infant care review committees. The Department of Health and Human Services did not view ICRC's as a substitute for the requirements of Section 504, but merely as an additional measure instituted to further protection for handicapped newborns and to promote quality medical decision-making.

Infant care review committees hold out a promise of significant benefits. They could make it less necessary for law enforcement agencies to intervene if they could guarantee that the rights of handicapped infants to normal care and ordinary medical treatment would not be violated. These committees could bring together some of the best minds in medicine, law and ethics to examine and resolve some critical problems in contemporary infant care.⁶

To study the moral responsibilities of infant care review committees, I shall begin by briefly surveying the views of various authorities on the roles and functions of these committees. Then I will examine some of the concerns and problems that have been expressed about ICRC's. Finally, the general and specific moral obligations of these committees to handicapped infants, parents, physicians and society will be studied.

I

Infant Care Review Committees: Their Role and Functions

The three general functions of infant care review committees will be examined here. Virtually all authorities and commentators agree that ICRCs can serve a general educational function for both health care facility staff members and the public at large. They also agree that these committees can review treatment proposals both prospectively and retrospectively. And ICRCs are also seen as agencies which could assist in the formation of guidelines, standards and norms for the care of handicapped infants.

The Educational Function of Infant Care Review Committees

While there is general agreement that ICRCs should educate health care facility staff members and the public at large concerning the care and treatment of handicapped infants, there is no unity on what

should be taught by these committees. The American Academy of Pediatrics asserted that these committees should educate parents about the means of treatment available in health care facilities and in a community for these children.⁷ However, these tasks seem to be better suited to other bodies, and most authorities agree that ICRCs should limit themselves to instruction in ethical matters. The most common view held is that infant care ethics committees should inform parents, physicians and health care staff members of their ethical responsibilities.

There is some debate as to whether ethics committees should merely provide a forum for the discussion of ethical issues, or whether they should assume an explicitly pedagogical role in which they would teach determinate ethical principles and rules.⁸ One leading authority has asserted that ICRCs should link societal values with developments in institutions, whatever that might mean.⁹ In contrast, some ethics committees in Catholic institutions have assumed a wider role and have aimed at teaching about the social implications of certain medical practices and policies, but this function has not been widely regarded as being necessary for infant care review committees.¹⁰

Infant Care Review Committees and Case Review

Almost all authorities agree that ICRCs have a role in reviewing the treatment given to or proposed for handicapped infants.¹¹ A number of writers have asserted that infant care review committees should not make decisions about the cases they review, but they are not clear on what they mean in saying this.¹² If this assertion means that ICRCs should not make medical decisions about treatments given to or proposed for handicapped infants, then no objections could be raised.¹³ It would seem that ICRCs, by their very nature, are to aim at coming to moral judgments about actions or treatment proposals, but to deny them the freedom to do this would be to defeat their primary purpose. That ICRCs should make ethical judgments does not mean that they should replace the traditional *loci* of medical decision-making, but it does imply that these traditional forms of medical decision-making should be subjected to strict ethical scrutiny and that all decision-makers should be held accountable for any irresponsible making ethical judgments about treatments and proposals for treatment. Most authorities do not object to infant care review committees making ethical judgments about treatments and proposals for treatment. But at the far end of the spectrum, some authors suggest that ICRCs should only decide who should decide about the provision of treatment.¹⁴ It is difficult to take this suggestion seriously, however, for shortly after making it, the author asserted that parents should make decisions about the treatment of children unless they are judged incompetent by a court.¹⁵ This view would unduly restrict the freedom of action of ICRCs and it is one that has not been shared by

many authors.

Case review can either be prospective or retrospective review of cases, it has been argued that committees should obtain all of the relevant facts of the case, identify the important issues, resolve differences between parents and physicians, and the composition of law complexity or difficulty of the cases and recommend intervention of almost all enforcement agencies if necessary.¹⁶ A serious problem is that of determining when ICRCs should intervene prospectively. Some have said that infant care review committees should intervene whenever life-sustaining treatments are proposed for withdrawal.¹⁷ Others have suggested that they only intervene when requested to do so by physicians, parents or staff members.¹⁸ Another difficult problem mentioned by authors is that of determining the authority of judgments or recommendations made by infant care review committees. Some claim that ICRC recommendations be binding upon those who treat handicapped infants, while others would hold that they should be binding on them in varying degrees according to the circumstances.¹⁹

When committees do intervene prospectively, there is little agreement among authorities as to how they should evaluate treatment proposals. Some assert that ICRCs should only require that "reasonable" or "appropriate" actions be taken in behalf of handicapped infants or that the "best interests" of the child be promoted.²⁰ Others have asserted that the dignity of the parents and physicians should be affirmed and promoted by ICRCs.²¹ But to my knowledge, few committees have notable authors recommend that infant care review committees intervene when the rights of the infant are in jeopardy. The absence of an affirmation of this should be a cause of concern, for it was in such a situation that the Baby Doe regulations were specifically promulgated.

In their prospective review of cases, some writers have suggested that ICRCs should not aim at reaching a consensus in their judgments, but should merely settle for a wide-ranging discussion of the issues.²¹ And virtually all authorities agree that courts and law enforcement agencies should only be allowed to intervene and investigate cases as a measure of last resort.²²

Policy and Guideline Formation

Most authorities hold that infant care review committees should have a role in the formation of policies and guidelines for the treatment of handicapped infants, but there is not much agreement on the nature of these guidelines.²³ No writers have suggested that guidelines contrary to institutional bylaws be adopted or endorsed by infant care review committees. Being predominantly procedural and formal, the guidelines which have been thus far proposed have not demonstrated that they could effectively protect the rights of handicapped infants in critical situations.²⁴ As there is little or no mention of these guide-

lines in Section 504 of the Rehabilitation Act, one can readily draw the conclusion that the primary objective of these guidelines is the protection of parents and physicians. Most authors claim that they wish to promote high quality medical decision-making, but they are not specific concerning the nature of this improved decision-making.

If any judgments concerning the moral responsibilities of ICRCs are to be made, it is not only necessary to understand their roles and functions, but also to grasp the problems and concerns which surround ICRCs. The aim of this next section will be to examine some of these problems and concerns before studying the moral obligations of these committees.

II

Infant Care Review Committees: Concerns and Problems

There are five general areas of concern with infant care review committees:

1) Probably the most significant concern with ICRCs is that they could really become dominated by the interests of one or a small number of groups or individuals to the detriment of physicians, patients and handicapped infants.²⁵ Reports have shown that it is relatively easy for physicians to dominate these groups and use them to promote their own private interests.²⁶ This problem has been less acute with ethics committees in Catholic health care facilities, as they have generally had greater diversity in their membership.²⁷ Virtually all authorities assert that infant care review committees should strive to attain diverse membership and thereby limit the harmful effects of domination by a single group or individual.

2) Holding infant care review committees accountable for their actions is another major area of concern.²⁸ ICRCs appear to have a problem similar to that which Institutional Review Boards (IRBs) had when they first began. IRBs often failed to adequately protect the rights of research subjects against immoral research, and it is thus feared by some that ICRCs could jeopardize the rights of handicapped infants by being neglectful of their duties to argue in behalf of their rights.²⁹ ICRCs appear vulnerable to this possibility, and most authors call for measures to make ICRCs accountable for their judgments and actions. Without such measures, it is quite possible that ICRCs could become culpable cooperators in unjust actions against infants.

3) A further problem with these committees is that their roles and functions appear to be so vaguely defined that they could readily abrogate to themselves the roles of parents, physicians, surrogate decision-makers, health care institutions, law enforcement agencies or the courts. This is a serious issue because it is not certain that ICRCs have the competence or authority to assume any of these roles completely. Related to this concern is that of the possible violations by

ICRCs of rights of privacy and confidentiality of interest parties because of inadequate procedural standards and regulations. To counter this possibility, many authors have strongly urged forceful measures to protect the privacy and confidentiality of involved parties.³⁰

4) There have been few reported instances of infant care review committees requiring excessive treatment, and it is quite possible that these committees might become biased in favor of unjustifiable non-treatment or nonintervention. A number of authors have argued that the activities of ICRCs be severely limited, and if these proposals are accepted, the power of these committees to require treatment could become severely restricted.³¹ This problem could be minimized if there were more specific and concrete guidelines for ICRCs, for the guidelines being proposed currently have little capability for compelling committees to require justified treatment.

5) Up to the present time, practically all of the procedures and guidelines suggested for ICRCs have been purely procedural and formal. This raises the possibility that ICRCs could intervene without justification or fail to intervene in review cases where intervention would be justified or morally required. Enactment of sound, precise, and substantive norms and standards has thus been recommended frequently.

In light of these problems and concerns about the procedures and functions of infant care review committees, it is now possible to discuss their general and specific moral responsibilities. While this discussion of their responsibilities will focus primarily on their moral obligations, some attention will be given to their legal obligations to the extent that these bear upon their moral duties and responsibilities.

III

The Moral Responsibilities of Infant Care Review Committees

Before discussing the general moral responsibilities of these committees, it is necessary to state that those who establish ICRCs have a strict moral duty and obligation to structure them so that they can fulfill their moral duties in full freedom. If ICRCs are so restricted in their actions that they cannot execute what is morally required of them, then any attempt to impose moral responsibilities on them would be futile.

Infant care review committees have four moral responsibilities in all of their functions and roles.

1) All ICRCs are bound via the duties imposed by what has come to be known as the Kew Gardens Principle. This principle asserts that all moral agents are required to take actions which do not entail grave risk for them if those actions would prevent another from losing a fundamental human good or from experiencing grave sufferings.³² For infant care review committees, this principle means that

they must take whatever actions are reasonably within their means to prevent handicapped infants from suffering grave harm or injury by either commissions or omissions performed by other moral agents.

2) All infant care review committees are under a common and ordinary moral duty to protect innocent human life from direct and deliberate lethal commissions or omissions.³³ This principle is correlative to the Kew Gardens Principle, but it states the nature of this obligation in more technical and precise terms.

3) In all of their actions concerning innocent human life, infant care review committees are morally required to adopt the morally safer course of action.³⁴ This does not mean that ICRCs must adopt the safest course of action in all circumstances, but only that they must act to guarantee that handicapped infants not be denied any reasonable chance for life and improved health. This principle does not endorse moral rigorism, for it promotes and encourages moral responsibility, prudence and respect for fragile and innocent human life.

4) All infant care review committees are morally obliged to promote, endorse and support laws and efforts of law enforcement agencies which seek to responsibly protect the moral rights of handicapped infants to ordinary medical treatments and care.³⁵ ICRCs are not meddling "do-gooders," exceeding their authority when they do this, but are only fulfilling a common and ordinary jurisprudential duty incumbent on all moral agents.³⁶ Because the law is more precise and specific than are moral principles, norms and rules, it is better able to protect the rights of all parties, and there is a moral duty to support it when it is administered responsibly. By doing this, infant care review committees are better able to fulfill their moral responsibilities toward handicapped infants.

These are the general moral duties of infant care review committees, but there are also some specific moral responsibilities of these committees which must be examined.

The Moral Duties of Infant Care Review Committees in Education and Case Review

In all of their case review activities, infant care review committees are to gather all possible relevant factual data concerning the cases. They are to studiously preserve privacy and confidentiality in doing this. All aspects of their reviews and investigations are to be properly and accurately documented and recorded.

When infant care review committees function in their educational role, they are to recall that their primary function is to instruct physicians, staff members and parents of their moral duties. ICRCs are not simply to provide forums for discussion, or aim at replacing legitimate regulatory functions of the government.³⁷ ICRCs are to take a pedagogical role in their educational activities because this is required by the principle that the safer course of action is to be followed. Infant

November, 1985

care review committees are to train health care professionals in their moral duties toward handicapped infants. They are to provide precise ethical guidance which, above all else, positively promotes the rights of handicapped infants, especially in difficult and complex cases. In this role, they are to instruct in the requirements of ordinary moral duties and in what is demanded by the safer course of action in various circumstances. And it is also a moral obligation of these committees to instruct parents and physicians in their moral obligations toward the law.

In their roles of retrospective and prospective case review, infant care review committees might not be required to make medical decisions, but that does not prohibit them from making ethical judgments about treatments or treatment proposals. To prohibit them from making ethical judgments is morally equivalent to prohibiting physicians from making ethical judgments concerning clinical cases brought to their attention.

In both prospective and retrospective case review, ICRCs are to take the safer course of moral action and intervene to review three separate kinds of cases. First, they are to intervene in a matter of moral obligation and make ethical judgments in cases where life-sustaining treatments are being proposed for withdrawal from handicapped infants, or where they are actually withdrawn.³⁸ This is required because there is imminent danger that the withdrawal of such treatments or care could be directly lethal or would be a violation of the rights of the infant to care and obligatory medical treatment. Second, infant care review committees are morally required to intervene in cases in which possible medically beneficial care or treatments are being proposed for withdrawal or have actually been denied to a handicapped infant. This is morally required because it is quite possible that grave harm could come to a child if such proposals or actions were carried out, and therefore, taking the safer course of action requires review. Third, infant care review committees are required to review cases where nutrition and/or fluids are being proposed for withdrawal or have actually been withdrawn.³⁹ Taking the safer course of action requires this because there are few, if any, situations in which denial of nutrition and/or fluids would not be direct killing. Whenever nutrition and/or fluids are of nutritional or hydrational value, whenever they can be successfully ingested by a human being, they are of benefit and should be provided unless it is physically impossible to do so. Nutrition and fluids are not medical treatments, but are basic resources of the body whose provision sustains life and whose withdrawal certainly causes death.⁴⁰ Their provision directly supports the natural functions of the body and its natural defenses against diseases. Because they are not specifically medical treatments, their provision should be regulated by principles other than those which govern the administration of medical treatments. Nutrition and fluids are aspects of normal care, and they should be

given whenever they can meet the nutritional and hydrational needs of the patient, as they are of benefit when they do this. There is nothing immoral whatsoever in feeding a patient if this will sustain life, and there very well might be something seriously immoral in denying nutrition and fluids to a patient so that death is brought about. Taking the safer course of action requires that one avoid the risk of unjust killing by providing life-sustaining food and fluids when they can preserve life. Food and fluids are different from medical treatments because they are not directly therapeutic as they do not directly and proximately correct or ameliorate clinically diagnosable conditions. If anything constitutes medical abandonment, it is the refusal to provide food and fluids to persons whose lives can be sustained by them. The Vatican recognized this in its *Declaration on Euthanasia* when it asserted that normal care was always to be given to patients, even to those who were terminally ill.⁴¹

In both prospective and retrospective case review, infant care review committees are to uphold the requirements of the law. Specifically, this requirement implies that infant care review committees are not to be used in any fashion to impede the enforcement of the law seeking to protect the rights of handicapped infants. They are to instruct individuals in their duty to report suspected cases of child abuse and neglect, and they are to reprimand individuals or organizations which fail to do this.⁴² ICRCs are not only to report cases of child abuse when they judge that there is sufficient evidence for a conviction, but even when there is only a suspicion that neglect or abuse is occurring. And in both retrospective and prospective case review, infant care review committees are to take steps to assure that their actions are carried out.

Infant care review committees also have specific moral duties in their role of assisting in the development of policies and guidelines, and these will be examined in the next part.

Moral Duties in Policy and Guidelines Formation

The fundamental duty of ICRCs in the development of policies, guidelines, norms and standards is to assure that these are not merely procedural, formal and subjective, but substantive, binding and specific. This is required by the principle of the safer course of action, as failure to demand this places handicapped infants in imminent danger. Guidelines cannot be merely "feasible," for these would not guarantee the rights of infants to obligatory medical treatments in complex and difficult situations. Guidelines cannot aim at being merely "reasonable," "appropriate" or in the "best interests" of the child, for these will not assure protection of the rights of the child to normal care and ordinary medical treatments. All of these criteria being proposed currently are purely procedural and formal, and by themselves they can-

not impose any specific concrete and practical moral duties on anyone. All norms and standards regulating the activities of care review committees must aim at concretely protecting the rights of handicapped infants above all else, as they are far more vulnerable than any other parties.

All norms and standards endorsed or promoted by ICRCs must be in full compliance with civil and criminal laws protecting the rights of handicapped infants against discriminatory acts. There is an implicit requirement in this demand which forbids ICRCs from endorsing policies and guidelines which violate the moral rights of physicians, health care institutions and parents. And it is particularly important that ICRCs endorse policies which protect the privacy and confidentiality of all individuals and parties involved in the treatment of handicapped newborns.

Recently it has been suggested that some handicapped infants be included in a treatment category called "supportive care only," in which no life sustaining measures or treatments would be provided.⁴³ Policies such as these, when suggested for handicapped newborns who are not imminently and unavoidably dying and for whom a nutrition and fluids would be life-sustaining, should never be endorsed by infant care review committees. There are instances in which palliative care could be provided morally because nutrition and fluids would not be ingested, but a policy permitting this for infants who are not imminently and unavoidably dying is immoral.

It has also been suggested by some authorities that "nontreatment" as a medical policy is morally legitimate when various kinds of other treatments would be of clear benefit to a child and when a "nontreatment" would do nothing to improve the child's clinical picture.⁴⁴ Adopting "nontreatment" as an option is not morally tolerable when positive measures would improve a child's condition or when the child is not imminently and unavoidably dying. Adopting a policy of "nontreatment" when positive treatments would promote the health of the child is nothing but a violation of the rights of the child by omission rather than commission.

There are quite a number of specific kinds and conditions from which infants can suffer, and in the next section, we will consider the moral responsibilities of ICRCs in respect to some of the more important afflictions of newborns.

Moral Responsibilities of ICRCs in Special Cases

It has been suggested by some authors that compassionate and humane treatment of infants with various conditions such as Lesch-Nyhan, Tay-Sachs disease, hydrocephaly, trisomy and other ailments be withdrawn or withheld.⁴⁵ The justification for this position is that the suffering experienced by children with these conditions is

so severe that death is preferable to life. This position is highly objectionable, however, because it is implied that nutrition and fluids would also be removed so that the children would be starved or dehydrated to death. As a result, these children are not killed by being allowed to die, but are rather killed by culpable omission. Denying the food and fluids would do nothing to improve their condition and it would introduce a certainly lethal cause which did not previously exist. Removal of nutrition and fluids does not cause the child to die due to a condition from which he or she is suffering, but rather it introduces a new culpable and immoral cause of death.

It has also been suggested that it would be morally permissible to bring certain handicapped newborns to death by directly killing them.⁴⁶ If it was judged that continued life was not in the best interests of a child, if the child suffered in the absence of treatment, and if death could be brought about intentionally, then it would not be immoral to directly kill a child, probably by lethal injection.⁴⁷ This is also quite objectionable because direct killing is never morally permissible, even when its motives are compassion and concern. Life is a basic and fundamental good and it can never become a burden to one in and of itself. The conditions from which one can suffer can become burdensome, but life itself cannot become burdensome. Giving lethal injections to infants makes physicians killers and it violates the medical canon of "do no harm." Death is never a friend of a child, and while it is not an absolute evil, it is never something which should be deliberately and directly chosen. The moral absolute against direct killing should be compared to the moral absolute against rape. While rape might bring some psychological benefits to the rapist, it is always wrong. Similarly, while direct killing of severely handicapped infants might bring some benefit to others, it is not something that should ever be chosen. Handicapped infants have an ordinary moral right not to be starved and dehydrated to death and they have an ordinary moral right not to be directly killed because someone thinks that they are suffering too much.

When considering treatments to be given to children with spina bifida, any and all treatments which improve the clinical picture of these children should be given. Any treatment which palliates, alleviates or corrects their clinical conditions and which can be given without undue burden to the parents or health care providers should be given as a matter of moral duty. Aggressive treatment of children with spina bifida should never be regarded as imposing harm on them when there is a prognosis that such treatment will improve the condition of the child. But where a child with spina bifida will die imminently and unavoidably, aggressive treatment which cannot ward off death can become morally extraordinary. Even in this circumstance, palliative care and provision of nutrition and fluids are morally required, as the life of the child is a basic good which should never be deliberately

destroyed or turned against by anyone.

"Do not resuscitate" orders should only be given for those handicapped infants who suffer from terminal illnesses and who are imminently and unavoidably dying. These orders should not be based on "quality of life" judgments, or on other standards such as the "benefit" or "burden of resuscitation, but rather they should be issued for handicapped infants when it is clear that death could be staved off by further treatment.

Tay-Sachs disease is often difficult to detect at birth, but it usually becomes markedly worse as the child grows older. Infants with this condition and with similar conditions should not be considered as being imminently and unavoidably dying, and therefore normal care which includes palliative and supportive care should always be provided. Only when medical treatments cannot forestall death can they be held elective, even though nutrition and fluids should be provided.

Conclusion

For all of the discussion of infant care review committees in recent months, it appears that such committees have been hardly utilized in the recent past. One study showed that hospital ethics committees were only used once a year on the average in those hospitals which had instituted them.⁴⁸ At the present time, there is a concerted effort to create a network of infant care review committees, and this effort should be regarded with caution. Many authorities admit that there are not experienced ethicists to be found on most committees, and this could lead to highly objectionable practices and judgments by those committees. It is quite possible that ICRCs could be used in the future as shields against legitimate intervention by law enforcement authorities, and this would be quite unfortunate if it were to happen. Thus, it is imperative that ICRCs adopt strict moral standards and that they be closely monitored during this phase of their growth and development. The existence and development of these committees are only tolerable if they enhance protection of the rights of handicapped newborns and if they facilitate enforcement of laws designed to protect their moral and civil rights. They cannot be allowed to become impediments to strict law enforcement, and for that reason it is imperative that a close watch be kept on them in coming months as they grow and develop.

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20. See Fleischman and Murray, *op. cit.*, p. 9; Levine, *op. cit.*, p. 10; and American Academy of Pediatrics, "Guidelines," *op. cit.*, VII, C, 7, p. 9.
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