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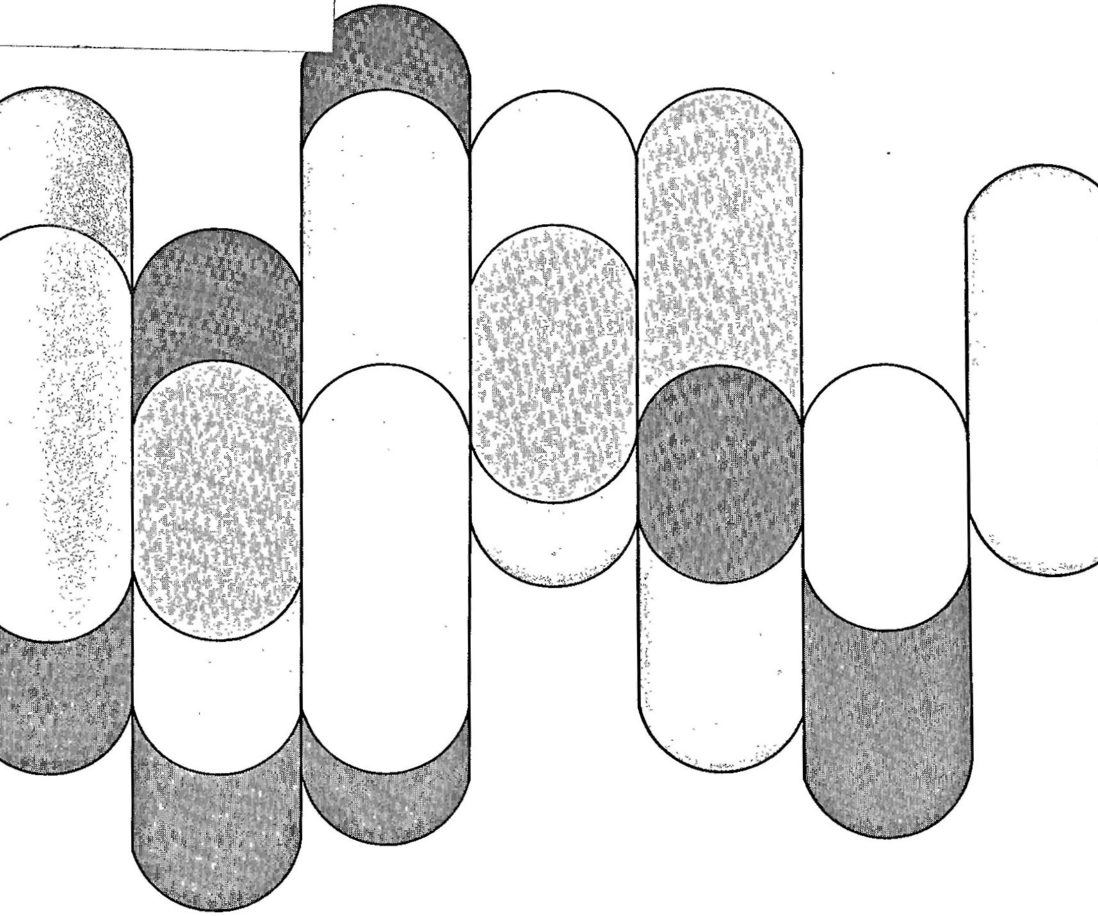

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ANENCEPHALIC INFANTS AND SPECIAL RELATIONSHIPS

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ABSTRACT. This paper investigates the scope and limits of parents' and physicians' obligations to anencephalic newborns. Special attention is paid to the permissibility of harvesting anencephalic organs for transplant. My starting point is to identify the general justification for treating patients in order to benefit third parties. This analysis reveals that the presence of a close relationship between patients and beneficiaries is often crucial to justifying treating in these cases. In particular, the proper interpretation of the Kantian injunction against treating persons as means only takes on a different light in the context of special relationships. The implications of this analysis for our responsibilities to anencephalic infants is clarified.

Key words: anencephaly, ethics, family, organ donation, physician-patient relations

INTRODUCTION

Is it morally permissible, or even praiseworthy, for parents of an anencephalic child to volunteer their offspring as an organ donor? Is it morally upright for physicians of anencephalic patients to continue futile treatment in order to respect parents' wishes? Typically, children who suffer anencephaly are stillborn, and live born anencephalic patients usually die within hours or days of birth. The cranial vault of such individuals is completely absent and their cerebral hemisphere either completely missing or reduced to small masses attached to the base of the skull. Despite this, late fetuses and live born anencephalic infants do not meet the whole brain definition of death: irreversible cessation of all functions of the entire brain, including the brain stem, has not occurred.[1] Although many organ systems in these children are underdeveloped, it is possible to utilize organs, such as hearts and kidneys, for transplant to other children. Importantly, successful transplantation typically calls for changes in the care we would otherwise give. For instance, if transplant is intended, physicians will attempt aggressive treatment, such as resuscitation, of a stillborn infant. They may induce labor in order to facilitate organ procurement, or prolong gestation in order to allow further growth and development of desired organs.

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THIRD PARTY BENEFITS

To address the ethical question of organ harvesting, let me begin by sketching a series of cases where we agree it is acceptable to perform invasive procedures solely to benefit a third party.[2] In each case we should try to locate the moral principle supporting these judgments. One kind of case is a sibling who decides to undergo surgery to donate a kidney to his brother. Here surgery is performed on one brother solely in order to benefit the other brother. But this is consistent with respecting the expressed wishes of the donor-patient. In this case, the presence of a close filial relationship between donor and recipient may well be a basis for the donor's decision. Yet even if it plays no role in the donor's decision, the presence of such a relationship may bolster the moral argument for treating.[3] If the beneficiary were a total stranger and the surgery imposed significant risks, the concern would arise that the donor is disavowing his own moral rights and viewing himself merely as a means to promoting a stranger's welfare. Such a choice is morally troubling because it raises the suspicion that the donor lacks self-respect: he acts as if his own rights are non-existent or insignificant. By contrast, the fact that the beneficiary is a brother helps to jettison this concern. It leads us to think that by helping his brother the donor is securing, rather than belittling, his own interests and goals. We are led to think this because the welfare of family members is of paramount concern to many people. Of course, it remains possible that a sacrifice for close relatives is morally problematic too, e.g., manifests a lack of proper self-respect or capitulation to coercive family pressures [6].

A somewhat different case is illustrated by an attending physician who continues intubation and other aggressive therapy for a patient beyond help and near death, and who does so for the purpose of protecting the patient's spouse who is ill-prepared for the death of his wife. We can imagine the physician's compassion for the spouse being consistent with the patient's own previously expressed wishes. For example, the patient may fervently believe that the dying are under a duty to the living, and that it is her duty and wish to help her husband come to terms with her death. She may have insisted on being allowed to fulfill this wish. In this second example, the physician's treatment may be commendable for its compassion towards the spouse and permissible with respect to not violating the patient's rights. In both this and the previous case, treatment intended to promote a third party's good is not morally inappropriate, because it is compatible with the patient's expressed and considered preferences. In this second case, moreover, the presence of an intimate relationship between patient and beneficiary plays a pivotal role. The physician would probably be considerably less comfortable continuing treatment to ease the suffering of a co-worker or second cousin. A justification that appeals only to the principle of respecting a competent patients' wishes may prove inadequate.

Another kind of situation is where a patient is not in a position to express preferences and is in a physical state that precludes physical discomfort or pain. For example, a patient in a persistent vegetative state (PVS) presumably lacks the capacity for consciously experiencing pain. One reason treatment to benefit a third party may be ethically acceptable in this case is that the principle of beneficence, and the corresponding duty to confer benefits, does not conflict with the relatively stronger principle of non-maleficence, and the associated duty not to impose harms. If the patient could be caused physical discomfort or pain, there pretty clearly would be a duty not to treat. Since the patient can experience no conscious pain, this objection is absent.

Another consideration relevant to deciding treatment when a patient's own wishes cannot be ascertained is the Kantian principle that we should not treat persons as means only ([7], p. 274). Even if a patient is incapable of being physically harmed, treating a patient solely in order to benefit a third party may constitute a wrong to the patient: it may involve regarding that patient merely as a means to another's end.

Figuring out whether benefitting a third party is consistent with showing respect for a patient who is unable to give or withhold consent requires determining whether the third party benefit is an end the patient holds. It must not be the case that an individual is treated to further an end that he or she could not possibly hold: e.g., prolonging dying in order to keep a physician's pride intact. A patient's ends can be reasonably estimated in a situation where the patient has a past record of preferences to draw upon. For example, it may be possible to construct an account of the wishes of a PVS patient who has a consistent history of stated preferences about aggressive treatment. The estimation of patients' ends is made more difficult in a situation of a minor organ donor. A minor donor may not yet have formulated values and ends. Still, it may be possible to extrapolate these based on what we anticipate the minor's future goals to be. The assessment of a patient's ends is rendered most problematic in the case of a minor whose death is imminent. Consider the case of a two or three year old in the last stages of a terminal illness. In this case, it makes little sense to extrapolate the patient's future ends. If no ends can be reasonably attributed, it might be thought that treating to benefit a third party could not possibly be justified by appealing to the fact that treatment conforms with the patient's own ends.

Upon closer inspection, however, such a justification may be possible. Think, for a moment, of a situation where the party-to-be-benefitted is the patient's best friend or parent, and where the benefit to be gained is especially valuable – e.g., life itself.[4] Invoking the Kantian idea of treating persons as ends is relevant, because performing procedures solely to benefit a third party may be precisely what treating a patient with dignity and respect *requires*. This is because treating individuals with dignity and respect requires attending to their unique identity. This identity is partly constituted by social roles and by a network of interrelationships. Respecting a patient's dignity requires considering this social dimension and, to the extent that a patient's ends merge with the ends of another, it requires taking that into account in making an assessment of the patient's own ends.[5] We can expect that an individual's ends will be linked with the ends of intimate others – e.g., friends, parents, siblings, and so on.

In some cases, then, benefitting an intimate other will be called for if we are to respect a patient's ends, because the welfare of another is an end the patient shares. In this situation, although the patient *is* valued as a means, the patient is *also* valued as an end. Thus, treating a patient to benefit a third party who stands in a special relationship to the patient is not on a par with treating to benefit a stranger. In the former case, the ends of patient and other are intimately connected and overlapping; in the latter case, they are severed and separate. Administering medical treatment to benefit a third party is *possibly* compatible with respecting a patient's end.

ANENCEPHALIC INFANTS AS PERSONS-IN-THE-SOCIAL-SENSE

Bearing in mind these general points, we are now in a position to reflect upon the responsibility of parents and physicians to anencephalic infants. This reflection will center on clarifying the ethical demands these relationships make. It will be useful to first focus the issue further by placing it in a more concrete context. We might begin by considering a recent protocol for procuring organs of anencephalic infants, established by an interdisciplinary group at Loma Linda University Medical Center [11]. This protocol seeks to avoid the problem of violating the presumption against transplanting organs from living human beings. It instructs physicians to alter the natural course of dying to facilitate transplantation in the following way. (1) Infants are not placed on respirator support at birth; instead, they are placed on respirator support and admitted to an intensive care unit (ICU) only after cardio-pulmonary failure occurs and death is seen as imminent. (2) If an outside neurologist establishes that brain death criteria are met within twenty-four hours of respirator placement, ICU care is continued and the infant is then registered as a potential donor. (3) If brain death criteria are not met within twenty-four hours, mechanical ventilation is withdrawn and death is allowed to occur without further intervention.

Is the Loma Linda protocol ethically supportable? One basis for justifying treatment to benefit third parties that is not available in this case is that patients themselves choose to undergo treatment. A second approach, and one that applies where a patient cannot formulate preferences, appeals to principles of beneficence and non-maleficence. This approach implies, first, that parents and physicians are not warranted in benefitting a third party if these benefits are purchased at the price of causing physical pain or discomfort to the patient. But anencephalic patients who possess only brain stem functioning lack the capacity to experience discomfort or pain. A final consideration is whether harvesting organs is consistent with the Kantian injunction that treatment should not involve using the patient as a means only.

Even if anencephalic infants are not persons in the Kantian sense,[6] wrong may nonetheless be done to the social role these infants symbolically occupy. We may feel compassion for the infant's plight, view the infant as the child of its parents, and as the patient of its doctor. To clarify the importance of our special regard for the anencephalic infant, it is useful to introduce Engelhardt's notion of person-in-the-social-sense ([12], pp. 116 ff.). Engelhardt uses this term to refer to beings that do not merit moral concern and respect in their own right, but to whom we nonetheless accord such concern. Such a status secures moral protections for individuals by virtue of the social role they occupy and is justified on utilitarian grounds.

By "person-in-the-social-sense" I intend to refer to a broader notion, one that applies both to persons and non-persons, but which can assume special significance in the case of individuals who lack the moral guarantees we accord to strict persons. Social personhood confers moral status on individuals by virtue of the place they have in the lives of others. For example, social personhood may be conferred on persons who stand in special relationships to others, e.g., as friends, patients, offspring, or intimate others. Thus, when we accord special concern to persons who are our friends or to non-persons who are our patients, the social sense of personhood is operative. Alternatively, social personhood may stem from recognizing an individual's membership in a group, such as a family, community, nation or species. When we feel special concern for the plight of American hostages, or special concern for our own family members, our justification is not that members of other nations or families are lesser persons (in the strict sense), but that we do not attribute social personhood to them in quite the same way.

Unlike Engelhardt, I consider multiple justifications for social personhood valid. In the case of anencephalic infants, a practice of treating individuals as persons-in-the-social-sense gains justification on various grounds. First, such a practice is justified if it is in fact widespread and if it does not create on balance more harm than good. In our society, infants, even defective infants, are indeed treated as if they were moral persons. This is evidenced by the fact that we object to exposing infants, and we do not sanction active euthanasia for defective newborns. This suggests that defective infants, at the very least, symbolically *represent* persons in our society. Moreover, the practice of treating such infants as if they merit moral concern in their own right supports important virtues, such as sympathy and care for fragile human life, and imparts an ethical dimension to the parent-child relationship at an early stage ([12], p. 117).

But it may be objected that this practice creates more harm, on balance, than good. After all, denying organs to potential recipients involves possibly sacrificing the lives of organ recipients. This utilitarian objection to treating anencephalic individuals as persons-in-the-social-sense initially appears quite convincing, but, upon closer study, it is much less so. If something resembling the Loma Linda protocol became widespread, or if laws changed to relax the requirement that anencephalic donors meet whole brain criteria for death, it is highly doubtful that this would significantly increase the overall number of available organs. This judgement is supported by the following observations. First, a growing number of women are undergoing prenatal screening for anencephaly and second trimester detection rates for this condition are ninety to one hundred per cent. Hence, fewer anencephalic infants are being brought to term [13, 14]. Second, anencephalic individuals that are brought to term may not possess eligible organs because malformations in organs of many anencephalic infants make them unsuitable for transplant. Third, even where organs are suitable, not all parents are interested in donating their offspring's organs. Fourth, even if suitable organs are donated, strict adherence to the Loma Linda protocol would prevent many organs from actually being procured in a useable form. This is because the protocol requires administering artificial respiration only after cardio-pulmonary failure occurs. But cardiac-respiratory failure quickly renders the heart, liver, and kidneys unusable due to poor perfusion of these vital organs ([15], p. 6). Finally, even if suitable organs are procured, only around twenty-five percent of all organ referrals (of all ages combined) are matched with recipients by established organ sharing networks. On this basis, it is reasonable to conclude that the yearly number of used anencephalic hearts and livers would not significantly increase the overall pool of organs available for potential recipients. In addition, the proportion of infant organ recipients who actually benefit in the long run from transplants is not entirely clear, as there has been so little experience to date with transplantation in such a young age group. It has been argued that a fifty percent long-term survival rate is "optimistically reasonable" [16].

A second reason for attributing to anencephalic infants the status of person-in-the-social-sense is that these infants are the subject of a human tragedy [17]. Unlike non-human animals whose mental life may be on par with that of the anencephalic individual, an anencephalic infant falls sadly short of what a human being can be. The birth of an impaired infant means that parents face and grieve the loss of an imagined perfect infant that was not born [18]. By contrast, the birth of a healthy guinea pig is not an occasion for grief. This difference has implications for understanding the moral status of anencephalic individuals. Attributing a special status to them is part of being alive to the tragedy of marginal cases. Those who equate the anencephalic individual with non-human animals or argue for subjecting these newborns to any treatment we would subject non-human animals of similar cognitive functioning to are overlooking a crucial distinction. Even if treating anencephalic human beings in this way does not violate their rights, it is a grossly inadequate response to human calamity.

A final reason that allows us to say that anencephalic infants can justifiably assume the role of moral persons in our society is that these beings *look* human. Analogously, even if we hold that only rational creatures are persons, we nonetheless ought to treat retarded or senile human beings as if they were persons. These beings *look* like fully rational beings. And the thought of seeing a senile adult treated like an animal, say fetching a stick for a master, rightly evokes disgust and outrage.

In the case of beings who look human but are not persons, a similar logic is at work. Since most humans are persons, if we learn that some actually are not, it may be appropriate nonetheless to accord them full respect. After all, we already have a deeply ingrained practice of treating beings who look human as persons. Hence merely looking human evokes potent moral responses in us. In the case of anencephalic infants, it is not the fact that these infants *are* humans that makes social personhood appropriate, it is rather the fact that we can *see* them emerge from a human womb, and they come forth *looking* human.

ANENCEPHALIC INFANTS AND SPECIAL RELATIONSHIPS

If the social sense of personhood *justifiably* applies to anencephalic infants, we then need to ask whether aggressively treating these infants in order to procure their organs is morally akin to treating them as objects to be used, rather than as beings to whom we accord moral personhood.

If we assume anencephalic human beings are persons only in the social sense, we can begin to grasp what respecting their ends implies. Whereas self-conscious and rational agents act to make certain ends their own, non-conscious or non-rational beings whom we treat as persons have certain ends constructed for them. As noted earlier, we construct ends for a patient in a persistent vegetative state on the basis of historical record, and we construct ends for healthy infants by extrapolating into the future their likely goals. In both of these cases, we attend to the history of close relationships and the prospect of future ones. We formulate the ends of a fatally ill infant in part by viewing it as a participant in special relationships and as a member of the broader moral community. Just as we suppose a pregnant PVS patient and her child have common ends, we suppose the ends of a newborn anencephalic infant merge with its parents' ends. Admittedly, this parent-child relationship is not as robust in content as it might be. It lacks an anchor in the past (as with an older child) or the future (as with a healthy child). Still, it provides one important source for constructing the infant's ends. Although the more traditional vocabulary of "person" and "non-person" confers moral status based on intrinsic features of individuals, in the case of fetuses and infants it is arguably more appropriate to emphasize other considerations. Namely, that the parent and child constitute a community of shared interests, not simply a group of individual actors, each with its own set of rights and entitlements ([19, 20]; [21], pp. 30–78, 120–124).

My earlier remarks suggest that the appropriateness of harvesting organs from anencephalic infants turns, in part, on the depth of parents' desire to benefit an organ recipient. If benefitting another child is an important end parents hold, e.g., because of the knowledge that donating organs offers a ray of hope to a sick child or that child's parents, we may then be able to justify something like the Loma Linda protocol. The idea is that such treatment does not involve treating anencephalic infants as a mere means, because the infant's ends are inextricably linked to the parents' ends and the treatment advances important ends parents hold. This approach displays the virtue of admitting multiple understandings of appropriate care. Whether or not procuring organs is morally licit depends upon the relationships and circumstances in which the infant is located and the specific content of ends specially related others hold. Parents are often well situated to carry out the dual tasks of articulating and protecting their offspring's ends, because out of parenting distinctive ways of conceptualizing, ordering, and valuing arise [22].

A final consideration concerns the responsibility born by physicians vested with the care of anencephalic patients. The ethics of the physician-patient relationship place physicians under a special duty not to harm patients [23]. Whether physicians actually injure anencephalic patients in the Kantian sense depends upon the motivation they have for procuring organs. Treatment intended to carry out parental wishes is sometimes ethically justified. But treatment intended solely to benefit a recipient or solely to advance a physician's research goals, is not ethically supportable. While the latter motive obviously falls short of respectful patient care, the former motive is suspect as well. In both cases, respectful patient care is rendered impossible because no attention is paid to the wishes of the person who gestates and bears the infant or the couple who together conceive the infant and invest its anticipated birth with expectation and significance. If my earlier arguments are sound, then attending to parental wishes is indispensable to understanding what it means to treat anencephalic infants as ends-in-themselves. Responsible stewardship requires physicians to consider the social role infants occupy. Physicians should avoid treating patients as means only, even if patients are, arguably, only persons-in-the-social-sense.

This paper has touched upon a complex array of individual, interpersonal, and social issues germane to the plight of anencephalic individuals. These issues should be born in mind both by parents who face donation decisions and by physicians who treat anencephalic patients.

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NOTES

[1] This definition reflects the Uniform Determination of Death Act [1]. Although the Special Task force of the American Academy of Pediatrics recently formulated guidelines for determination of brain death in children, these guidelines are not useful for premature or anencephalic infants (see [2]).

[2] The discussion in this section borrows from Mark Yarborough [3].

[3] It may be objected that showing special concern to those who stand in special relationships to us violates a requirement of impartiality and that a moral point of view must uphold this requirement (or is even defined in terms of it). This objection is suggested, for example, by Peter Singer ([4], ch. 1–2). I am not at all convinced that impartiality does require this. For further discussion of this point see [5].

[4] It is sometimes argued that a child owes his or her parents a debt of gratitude for having received from parents the gift of life. For a general discussion of this idea see [8].

[5] Michael Sandel suggests an argument to this effect ([9], pp. 144 ff.). Sandel maintains that utilitarianism avoids the objection against using persons as a means to promote the welfare of others if it can be shown that special bonds exist between the individual or group whose welfare is promoted and the individual(s) who is a means to promoting it. (See also [10].)

[6] Kant himself would not consider the imperative to treat persons as ends relevant to anencephalic infants. Kant thought that only rational creatures are persons who merit respect in their own right.

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