THE SEPARATION OF CRANIOPAGUS CONJOINED TWINS: A BIOETHICAL ANALYSIS

by

J. Grady Crosland, M.D.

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Approved:

Thesis Advisor: _______ (recently deceased) ____________
Harold O. J. Brown, Ph.D.

RTS/Virtual President: ____________________________
Dr. Andrew J. Peterson

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ABSTRACT

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J. Grady Crosland

A particular medical case involving the separation of craniopagus conjoined twins is chronicled and an ethical analysis of the decision to undertake the operation is offered. A general review of different schools of ethics and their history is provided. A review of the history of medical ethics and its precepts as understood in the present culture and its application to the case under examination is also proffered. The purposes of medicine are discussed referencing professional medical societies and contemporary bioethicists. The church’s history with respect to medicine and a discussion of anthropology complete the background for formulating a philosophical grid of ethical judgment. Lastly, a review of the medical literature reveals technical advances as well as insight into the ethical thinking of those who are involved with the actual separation of conjoined twins.

The roles of the hospital Ethics Committee and the hospital chaplain’s within that committee are addressed.

This case can be utilized by medical students, physicians, medical ethicists, seminary students and professors of practical theology to examine a particular, rare and complex situation to reveal many different aspects to be considered in developing their personal medical ethics. The fact that the results of the surgery were the “best case” scenario sought by the operating team is not a de facto affirmation of its ethical process.
This thesis is dedicated to the many people who have guided me in the pursuit of understanding the present culture through the lens of the Reformed theological perspective; and, in particular, to Mrs. Alice Hathaway, the infrequent face but the often needed voice of encouragement and information representing the Virtual Campus as a true sister in Christ
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INTRODUCTION

A Chronology of Craniopagus Twins

A set of craniopagus conjoined twins was born in Qus, Egypt, approximately 500 miles south of Cairo, in June 2001. A prenatal abdominal sonogram had foretold their arrival. They were immediately transferred to the University of Cairo Abu el-Reesh Hospital and placed under the care of Dr. Nassar Abdelal, head of neonatal surgery. As the parents were poor uneducated rural people, Dr. Nassar was given medical guardianship of the babies and they spent the first year of their lives in the hospital.

The physicians in Cairo did not feel they could assemble the medical expertise and resources necessary to perform separation surgery. They searched worldwide for possible assistance. As the incidence of this type of twinning is present in approximately one in 2,500,000 live births, expertise was severely limited. Several medical centers expressed interest in aiding the Egyptians. Issues of finance, travel and maintenance, and history of previous surgical experience and success had to be considered.

A foundation in Dallas led by a world-renowned cranio-facial surgeon agreed to underwrite all the expenses to bring the boys to Dallas and perform the tests necessary to
determine if separation surgery was even feasible. The foundation and the surgeon were familiar to an Egyptian pediatric surgeon who had observed surgery and the foundation’s work for several months a few years before. His high opinion of the medical resources and the lack of substantial financial obligation to the family or the Egyptian government were significant factors in the decision to take the twins to Dallas.

Dallas has two pediatric hospitals offering tertiary care. Both were intimately involved in the care of the twins. One provided pre-op and floor post-op care and one provided the immediate pre-op, operative, and post-op ICU care. The sophisticated technological pre-operative assessment required the duplication of many studies done at the initial hospitalization in Dallas because of less than ideal equipment and/or differences in operator technique.

After nearly six months of evaluation it was deemed medically possible to separate the twins.

The medical ethics committees of both hospitals approved the surgeries. In April of 2003 the twins underwent surgery for the placement of tissue expanders in the heads necessary to cover the brains at the time of the separation surgery.

Meticulous preparation took place to prepare for the separation surgery including the creation of a customized operating table. The operating teams (one for each twin) went through several mock runs prior to the actual surgery.
The surgery began October 11, 2003, and lasted 33-34 hours. Both twins spent several days in the Intensive Care Unit and approximately two weeks on the floor before being transferred to the other pediatric hospital for further care, particularly rehabilitation.

The twins returned to Egypt more than three years after their arrival to Dallas. At the time of this composition, one twin requires a walker; the other now walks without aid. Both have unilateral motor weakness. One is more limited than his twin in speech development. Balance, dexterity and speech are expected to improve over time.

The outcome is declared an overwhelming success by the parents, the medical team, the hospitals and the media.¹

Is Something Rotten in Denmark?

I was included in the earliest meeting of the formulation of the medical team to care for the twins. I had twelve years of pediatric cranio-facial anesthesia experience at the time and had participated in the separation of two pairs of conjoined twins, neither of which was joined at the head. I had done very extensive pro bono work both domestically and abroad. I was assuming I was being offered the opportunity to recruit and provide leadership for a team of pediatric anesthesiologists necessary to this endeavor. My assessment may be in error or the offer was made by someone not in authority to make such a request. As I was not inclined to accept such a role nor to even participate, the matter is moot. There were

¹ Personal communication from the executive director of The World Cranio-Facial Foundation and the Winter and Fall publications (2005) of Medical City Children’s PediViews.
enough “signs” for me to ascertain that I did not wish to be a part of this team. I still think that was the right decision for me. The body of this paper will delve into ethical as well as pragmatic issues that substantiate my choice of non-participation in spite of the team most admirably achieving its goals.
SCHOOLS OF ETHICS

Let us begin our journey by examining chronologically the history of ethics in the Western tradition: for ethical codes guide the day-to-day behavior of the culture which adheres to them. This examination should allow us to determine how contemporary ethics are both dynamic and syncretic. Frequently more than one ethic is influential within a complex culture. The following summaries are neither exhaustive nor detailed. They are intended to simply create a gestalt to provide a general understanding to the novitiate of philosophy. An academic approach, in the opinion of this author, is superior to the existential one often espoused by the uninformed.

Virtue Ethics

Ancient civilizations have left law codes for archeologists to ponder. Within any law code is a foundational ethic, whether explicit or implicit. Hammurabi’s Code of approximately 2000 B.C. is such a document. Its prologue speaks of the pursuit of righteousness; articles 218-223 (out of 282) provide specific guidelines for physicians.

The most influential ideas upon Western civilization have been those of the ancient Greeks. They have left us the writings of Plato who shares with us the teachings of Socrates; and of Plato’s pupil, Aristotle, who has left us his Nicomachean Ethics. Plato (in his dialogue Philebus and in Book IX of The Republic) and Aristotle address the concept of the
“good life,” one that is admirable because it is a life of virtue. Virtuous people have *eudaimonia*, “happiness,” or better, “well-being.” Plato enumerates the virtues one must possess in order to pursue the “good life” in *The Republic*. They are temperance (self-control), wisdom, justice, and courage. Aristotle sought a Golden Mean (moderation) between excess and defect. We call such an ethic Virtue Ethics. Thomas Aquinas adopted this foundation to propose his three virtues of faith, hope, and charity. The emphasis is on character, not duty. The disposition is fundamental; the action is derivative.

Socrates addresses moral philosophy in Plato’s *Crito*. Regarding ethical thinking, he provides the following caveats:

1) Thinking should be reasoned, not emotional.
2) There should be no appeal to general thought.
3) One should never do what is morally wrong.
4) There exists a hierarchy of moral duties.

Socrates also notes three types of thinking. The first is descriptive, empirical inquiry. It is of non-moral value. The second is normative thinking. It implies “ought” and “right/wrong.” It includes judgments of both moral obligation and judgments of moral value. The third type of thinking incorporates analysis, criticism, and meta-ethics.

Western civilization has as its repository of ethical concepts the institution of the Roman Catholic Church and its interpretation of Scripture from the fourth to the eleventh centuries. Thomas Aquinas’ contribution of natural theology engages Aristotle’s work to some extent. The Roman Church’s modus operandi in re bioethics since Aquinas has
primarily been the rationalism of moral theology. The Renaissance spawned the Enlightenment which adopted the dictum of Pythagoras (5th century B.C.) whereby man rather than God is “the measure of all things.” The Protestant Reformation paid scant attention to medical ethics beyond the direct commands of scripture. Immanuel Kant became a skeptic in the formal sense with respect to divine command ethics; but his treatises on practical thought revealed deep faith in the noumenal. Two schools of ethics then arise, each with its strengths and weaknesses.

Utilitarian Ethics

The second school to note is that of Utilitarianism. It focuses on extrinsic goodness – good as a means to something else (good). Inspired by David Hume’s Treatise of Human Nature, Jeremy Bentham made the assumption that “Nature has placed mankind under the governance of two sovereign masters, pain and pleasure. It is for them alone to point out what we ought to do, as well as to determine what we shall do.” In 1790 Bentham published his Introduction to the Principles of Morals and Legislation. In it he postulated his Principle of Utility as follows: that action is right that produces the greatest amount of pleasure for the greatest number of people. The altruistic hedonism for “the greatest number” is in contrast to egoistic ethical hedonism where an individual considered his own pleasure the highest good. Bentham’s godchild (literally) was John Stuart Mill. He, like Plato, recognized that pleasure and the good are not equivalent. His Principle of Utility was slightly altered from Bentham’s. He exchanged happiness for pleasure and distinguished classes of pleasure.
G. E. Moore published his *Principia Ethica* in 1902. He formulated the concept that “That action is right which produces the greatest good.” He also considered the possibility of “goods” other than pleasure and happiness. The greater the number of people who experienced good was of itself a greater good. The Achilles’ heel of Utilitarianism is considered to be its lack of justice. The possibility of some suffering significantly in order for the masses to benefit greatly (the greatest good for the greatest number) was excluded by Moore’s impersonal consequentialism – the counting of all people’s good equally.

Utilitarianism and consequentialism are often used interchangeably. Consequentialism defines the rightness or wrongness of an action in terms of its consequences. Actions are justified by the amount of good they bring about. Consequentialism is more concerned with the greatest good than with the good of the greatest number (contra utilitarianism). Both can be further divided into act-utilitarianism and rule-utilitarianism. Act-consequentialism says that an act is obligatory if it promotes better consequences than any of its alternatives. Rule-consequentialism asks “Which general rules will promote the best consequences in the long term, assuming universal compliance?” Consequentialism is socially rather than personally oriented. Both virtue and utilitarian ethics are non-foundational, relativistic schools.

**Deontological Ethics**

Deontology (from the Greek *deon* meaning “necessary being”) defines the rightness or wrongness of an action in terms of a duty or obligation to will the good. Immanuel Kant
provided the rational approach to this ethic. He postulated that there are rational laws of
morality that are objective and universal that are to be discovered, not invented, that he titled
“categorical imperatives” which ought to be obeyed. His formulation – to act in such a way
that you can will your maxim (the rule of conduct you have under consideration at that time)
to be a universal law – is similar to the Golden Rule. Contra utilitarianism, Kant’s corollary
was to act so that you always treat other rational beings as ends, never as means.
Consequences, feelings, and desire are derivative, not determinative, in this construct. These
imperatives or laws are neither heteronomous nor theonomous. Basically, if you obey the
impersonal categorical imperatives, you will achieve the right consequences.

W. D. Ross, an American ethicist of the early-mid twentieth century, considers the
distinction between act and action in his The Right and the Good published seventy-five
years ago. It preserves the best elements of both consequentialism and deontologism but,
like virtue ethics, is concerned with a person’s motivation. Ross examines the “act” – the
“outside” of something that we do that concerns itself primarily with the “fittingness” of
what we do. It asks, “Is this the right thing to do?” The “action” looks at the “inside” of our
behavior (motive/reason) that is good or bad. He posits a grid of four combinations of
behavior and motive: imperatives are derivatives of it.

1) Right act and good action (right thing to do for the right motive)

2) Right act and bad action (right thing to do but for wrong motive)

(This is not a novel idea. Sir Thomas Browne captured its essence in 1760 in his Christian
Morals with this admonition: “Stain not fair Acts [sic] with foul intentions.”)
3) Wrong act and right action (wrong thing to do but with pure motive)

4) Wrong act and bad action (wrong thing to do and for wrong motive).

Liberalism is an ethical philosophy granting people the right to act and live in accord with their own conception of a good life, provided it does not interfere with the rights of others to do the same.

William K Frankena published his Ethics in 1963. In chapter 3 he discusses agapism, which he defines as “the one basic ethical imperative is “to love” – all other imperatives are derivative of it.”¹ The foundational premise is that morality was made for man, not man for morality. Love is what underlies and unifies the rules of morality. Agapism (from the Greek agape, “love”) may be divided into act agapism which requires one to perform the most loving act in a situation (Joseph Fletcher, the Boston theologian and academician who founded the school of situation ethics) and rule agapism, which asserts that there are specific moral laws that inform us how love is to be expressed. Benevolence is one product of agapism.

There is still another form of deontologism – the nonagapistic or divine command ethic. Its premise is that we ought to imitate/obey God. It presupposes a special revelation and the reception of the laws of God. Both the Muslim Koran and the Christian Bible hold this premise. Romans 2:14-15 declares that the gentiles who did not know the law of love still have a moral law “written in their hearts.” (Therefore there is something greater than agapism.) It also connotes that the love ethic is not synonymous with the benevolence ethic.

“Thou shalt love the Lord thy God” is a command given by God for man to act that is without benevolence to God because one of His attributes is aseity.

Casuistry is the ethical method of examining particular cases to arrive at general principles. It denies the primacy of principles and focuses on analogical thinking. Cultural relativism denies the criteria of objectivity and impartiality that define ethical theories. According to cultural relativism, there are no universal truths, only cultural codes that vary from one culture to another. No code has any special status.

There are many available sources describing the above information. I have particularly drawn upon Walter Glamon’s Biomedical Ethics, Chapter 1, “History and Theories,” (Oxford Univ. Press, 2004); Robert M. Veatch’s Medical Ethics – An Introduction, “The History of Medical Ethical systems,” (James Bartlett Pub. 1997); Patrick Grim’s lecture series “Questions of Value,” (The Teaching Company, 2005); and lecture notes of Ronald Nash’s course “Christian Ethics,” (Reformed Theological Seminary, Virtual Campus, 2000).

The Christian Ethic

Does scripture lead us to believe that a particular ethic discussed above is representative of a Christian ethic?

Professor John Frame’s Medical Ethics is an answer to this question. He uses his common modus operandi of the trilogy via a normative, situational and existential approach to examine the problem or situation, the scripture and the problem and an analysis of the
person, respectively. He finds that scripture evaluates moral actions, thoughts, and attitudes in four ways:

1) Prohibition – “Thou shalt not…”

2) Permission – “You may…”

3) Commands – incorporating the principle of beneficence (“Love your neighbor…”)

4) Praise – commendable, but not required (Anna in the temple).

Frame believes that risk, benefit and cost (harm, beneficence, and justice) are biblical concepts. He also holds that there exists a hierarchy of importance of principles, and that there is a priority of divine mandates. Lower authorities may be disobeyed; God may not be disobeyed. Some biblical commands are directed to the individual; some are directed to the whole culture or church. Only God declares exceptions. Development in redemptive history and cultural changes affect certain principles.²

In the Divine Command Ethic, actions are right, good, and obligatory because God says they are. Plato attempts to offer an argument against this ethic in his Euthyphro. But his “straw man” of the gods does not capture the ontology of the Judeo-Christian God whose very essence defines “right/holy.” A second argument contra the Divine Command Ethic is that the existence of God cannot be proven empirically. “It is wrong always, everywhere, and for anyone, to believe anything on insufficient evidence.” according to W. K. Clifford

as recorded in his “The Ethics of Belief.” Professor Frame addresses that issue in his The
Doctrine of the Knowledge of God. He exposes the limitations of empiricism by its
dependence on senses that can be deceived, verifiability that would require an ad infinitum
process, its limitations with respect to general statements, the future, ethical values, and its
inability to even verify itself. In short, Frame concludes that empiricism is inadequate as a
general theory of knowledge.³

THE PURPOSES OF MEDICINE

The purposes of medicine have been compiled into lists by various authors interested in medical ethics.

Steven Miles of the University of Minnesota Medical School lists three common goals:

1) To allow healing
2) To palliate suffering
3) To enable patients to enjoy life.

Jonsen, Sigler and Winslade have an expanded list that includes the following:

1) The restoration of health
2) The relief of symptoms
3) The restoration of function
4) The saving or prolongation of life
5) The counseling of patients
6) The avoidance of harm.¹

Note the difference in the first list of “to enjoy life” and in the second “to save or prolong life.”

Edmund Pelligrino takes a different tack in discussing “the act of medicine” – making the technically right and the morally good decision that best serves the needs of the sick.

person as grasped by that person and his/her physician. He notes that patients need help, healing, caring, and curing.²

Christ’s miraculous healings accomplish several things. He restores the afflicted to physical, mental, or spiritual health. His healing allows the recipients to engage in the fullness of life’s activities. It also makes them eligible to participate in temple worship. His restoration is a sign of the restoration to come at the parousia into a glorified body without decay. The manifestation of His power and compassion reveals Him as the Son of God.

A HISTORY OF MEDICAL ETHICS

Biomedical ethics is a subset of the broader concept moral philosophy. Its Western tradition can be traced to the fifth century B.C. in the School of Hippocrates. The Hippocratic Oath, still administered at medical school graduations even today, includes the statement “I will use treatment to help the sick according to my ability and judgment, but never with a view to injury or wrongdoing.” From this statement evolved the Latin maxim *Primum non nocere* (“First do no harm.”).

As early as the *Summa* of St. Antoninus (1389-1459), the duties and obligations of physicians were enumerated and included the following: competence, diligence, care for the patient, the obligation to inform the patient if he/she is dying, appropriate fees, to care for the poor without compensation, and an obligation not to proscribe things contrary to moral law.¹

The turn of the nineteenth century saw several authors of various professions pen both the attributes and duties of a physician for general distribution. The Anglican clergyman Thomas Ginsborne wrote *An Enquiry into the Duties of Men in the Higher and Middle Classes of Society in Great Britain Resulting from their Respective Stations, Professions, and Employments* in 1794. Chapter 15 “On the Duties of Physicians” he presupposes that the medical student has already received a gentleman’s classical education and follows the “higher duties” of public worship and serious study of the Scriptures. He

warns the new practitioner not to put on “airs’ nor to assume that one knows more than one actually does. The English physician Thomas Percival is the first to coin the term “medical ethics” in 1803. His American classmate Samuel Bard was a founder of the first medical school in New York. Bard penned a treatise “A Discourse upon the Duties of a Physician.” He admonished his young graduates with the caution:

Where the Object is of so great Importance as the Life of a Man; you are accountable even for the Errors of Ignorance, unless you have embraced every opportunity of obtaining Knowledge.  

Neither the medical school in Edinburgh (the most prestigious in Great Britain at the time) nor those in Philadelphia or New York paid more than lip service to the Hippocratic Oath. Its recitation was simply a rite of graduation at some schools and was entirely ignored at others. The Oath required care be given to all and stated recompense was to be made to the physician according to the patient’s capacity to pay. It acknowledged some would be unable to pay anything. (For an excellent treatise on the Hippocratic Oath, see Ludwig Edelstein’s The Hippocratic Oath, Text, Translation and Interpretation, Supplements to the Bulletin of the History of Medicine no. 1, editor Henry E. Sigerist, Baltimore, The Johns Hopkins Press, 1943.) Bard emphasized the moral duty of physicians to care for the poor.

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Percival not only iterated the concept of nonmalefice (not harming) but also added the concept of beneficence to that of the physician’s acts of responsibility.

Medical societies promulgated codes of ethics for the next century and a half. They were written by institutional medicine for the medical guild.

Protestantism as an institution had little to say about medical ethics because “the good of the patient” was equated with good medicine and was sufficiently identified with moral theology so as to be indistinguishable.

Roman Catholicism, on the other hand, had a long history of church regulation of subjects such as contraception and sterilization. Paolo Zacchia authored *Questiones Medico-legalae* in 1621 defining the relationships between law, medicine, and theology. In the Roman Catholic tradition, the individual’s choice was subordinated to the good of the species as a whole. Vatican II responded to the boom in bioethics with a shift from classicism with deductive reasoning with abstract absolutes to historical consciousness with inductive reasoning resulting in a less fixed, though more particular ethic. The “good of the patient” was being challenged by the “good of science” as being nobler than the good of a single individual. In the case of organ donors, intentional harm was being done to some in order to benefit others broaching the oldest of medical ethical dicta, “First do no harm.”

H. Tristram Engelhart, Jr., in his *The Foundations of Bioethics: Rethinking the Meaning of Morality*, makes several cogent sociological observations about the state of affairs in the last half of the twentieth century. First, he noted the transition of the medical

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3 Curran 116.
profession from one of a guild to that of a trade with its attendant deprofessionalization. (When I enrolled in medical school in 1970, there were 100 students, 10 of whom were female and two of whom were black. Thirty were sons of physicians. Very few were not sons or daughters of professionals. This class led the nation in National Board scores for 5 years. Now classes have racial, geographical and gender quotas. The percentage of students with parents who are professionals is small.)

Second, Engelhart noted the rapid secularization of the American culture in the post-modern world with its disestablishment of religious leaders as authorities in the arenas of public opinion. Concepts such as “creation” and “humankind” which had had deep meanings for all of Western Christian history lost their intrinsic meanings. In the aftermath of the “God is dead” mantra a sequence of history remains, but without intrinsic meaning. In so far as meaning does exist, it is “conveyed by persons within interpersonal frameworks of particular narratives, discourses, or cultures.” If the presupposition is accepted that God is dead for the human culture, then human nature loses its canonical moral significance and man becomes “the measure of all things.”

The field of bioethics came into being to fill the void created by the deprofessionalism of medicine and the secularization of American culture. A plurality of moralities has since arisen, each contingent on its own presuppositions, each suffering

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significant limitations of their respective epistemologies, and each subject to criticism that they are little more than a particular popular whim or simple preference.

Edmund Pelligrino is one of the fathers of modern bioethics. His four years of study of both theology and philosophy in his undergraduate days at a Roman Catholic university set the foundation for a career in medical ethics. He is a self-described Thomist-Aristotelian, encompassing both faith and reason. His passion has been to articulate a philosophy of medicine based on the nature of the medical relationship. Its tenets include the following:

1) It acknowledges the fact of a person who is seeking help.
2) There is an act of promise by a physician who offers help to the ill patient.
3) There exists “the act of medicine” – making the technologically right and the morally good decision that best serves the needs of the sick person as grasped by that person and his/her physician.

The primacy of the good of the patient is the *locus ethicus* of the relationship. It seeks “a right and good healing and helping act.”

Pellegrino asserts that “certain character traits are entailed – fidelity, trust, benevolence, truth telling, intellectual honesty, humility, courage, suppression of self-interest – at a minimum. These traits are not entailed because they are admirable, they are admirable because they are essential to achieving the ends and purposes of medicine.”

Philosophically, he acknowledges the pluralities of understanding both “the moral good” and anthropology. He clings to the cultural and philosophical past in claiming that moral philosophy must give account of religious and theological sources of moral authority;
otherwise it becomes a tool of politics or a social convention. Ethics should not be a matter of polls or plebiscites.⁵

Tom Beauchamp and James Childress, both graduates of Yale Divinity School, have penned several editions of *Principles of Biomedical Ethics*, the first published in 1976. They have derived four clusters of moral principles; though they are actually four norms rather than formal philosophical constructs. They are the following:

1) Respect for autonomy (not simply autonomy per se) – a respect for the decision-making capacity of autonomous persons (e.g., patients)

2) Nonmaleficence - the avoidance of causing harm

3) Beneficence – the provision of benefit and consideration of the risk to benefit ratio

4) (Distributive) Justice – fairness in the distribution of benefits and risk.

In Beauchamp’s moral philosophy, autonomy refers to personal self-governance. Autonomy means freedom from external constraint and presence of mental capacity for understanding, intention, and voluntary decision-making.

Beauchamp addresses casuistry – the method using cases whose moral features and conclusions have already been decided and then compares the salient features in the paradigm cases with the features of cases that require a decision using analogical reasoning (similar to case law). He notes that even casuistry cannot dispense with principles.

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⁵ Pelligrino, Edmund, “From Medical Ethics to a Moral Philosophy of the Professions,” *The Story of Bioethics* 6-14.
Beauchamp’s critique of Pellegrino is that for Pellegrino medicine is “praxis and not theory.” Pellegrino’s one external principle - beneficence - sits in judgment of medicine’s internal standard. Beauchamp promulgates the theory that communities define medicine and healing, not the physician-patient relationship. Beauchamp dismisses the idea of universal principles as standing above the particular norms of particular cultures as a bankrupt one.\(^6\)

Robert M. Veatch is yet another significant contributor to the library of bioethics. His A Theory of Medical Ethics contains five major themes. The first is the obsolescence of the Hippocratic oath as it is individualistic, consequentialist, and paternalistic. The second is that there exists a triple contract in bioethics. It is a blend of secular contract theory and covenantal theology. It claims that it is possible to identify universal moral norms of a culture, there is a contract between health consumers and providers, and that there is a contract between individual health consumers and health providers. His third theme is that beyond patient benefit and protection from harm lays the avoidance of killing and the recognition of patient autonomy. Fourthly, beneficence and nonmaleficence should be seen in sociological terms, not simply individual ones. Lastly, there is a hierarchy of principles; and primum is patient autonomy.

In summary, Veatch holds to a common morality with a hierarchy of principles in which the patient’s autonomy is greater than the patient’s good.\(^7\)

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\(^7\) Veatch, “A Theory of Medical Ethics,” The Story of Bioethics 69-84.
In Disrupted Dialogue Veatch attributes marked changes in the ethical attitudes of the laity towards institutional medicine to the Social Rights movement of the 1960’s. Four major tensions emerged. Liberal political philosophy abandoned consequentialism for deontologism to accommodate autonomy and justice. In the same vein it advocated individualism apart from society as a whole. Paternalism, the practice of the “father” physician exercising a caring, superior and authoritative manner toward the “child” patient in which the patient accepted without question the decisions and recommendations of the physician fell to the sword of egalitarianism. Lastly, casuistry was replaced by a rules-based approach advocated by John Rawls.8

Baruch A. Brody, an orthodox Jew, argues “that only a pluralistic account of morality supported by, and in turn supporting, a radical casuistry that can account for the moral universe” is relevant in determining the rightness or wrongness of actions. This is as recently as 2003 in his text Taking Issue: Pluralism and Casuistry in Bioethics. He forsakes the monism of both deontology and consequentialism. He uses a form of intuitionism that seeks principles from particular actions. He claims four notions of objectivity in his moral knowledge paradigm: it has truth conditions without reference to feelings or emotions, it is universalizable, it is methodological, and it has interpersonal agreement. Beauchamp and Childress attack the lack of interpersonal agreement and Veatch criticizes the absence of a

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8 Veatch, Disrupted Dialogue 212.
method to “weigh” or “measure” moral appeals.\(^9\) (Yet this approach is the *de facto* methodology utilized in the medical ethics modules of most medical schools.)

With the rejection of all symbols of authority and the concept of medical paternalism in particular, medical ethics came to endorse patient autonomy as the *sumnum bonum* and social justice as the penultimate measure of medical ethics. The need for autonomy goes beyond the inadequacies of paternalism. *The Practice of Autonomy* by Carl E. Schneider, published in 1998, portrays a major disconnect between physicians and patients. Doctors come with a bias, think differently from patients, may lack experience of the patient’s problem, view their task differently from the patient, and have relationships with hospitals, insurance companies and health management organizations with goals different from the patient. Add the use of euphemisms, the quoting of “odds,” and the filter of fear and impotency with which information is filtered and you have all the makings of an adversarial relationship. To that concept add the observations of Irving Janus and Leon Mann – two leading students of decision – that man, when faced with the challenge of making an important decision, is reluctant,

beset as he is by conflict, doubts, and worry, struggling with incongruous longings, antitheses, and loyalties, and seeking relief by procrastinating, rationalizing, or denying responsibility for his own choices.”\(^{10}\)


However, another voice still persists. Warren T. Reich, editor of *The Encyclopedia of Bioethics*, makes the following observation:

Since the Enlightenment the goal has been to remove all religious “myths” so that a myth-free science would remain in the ascendancy and religion would simply fall away…it has not turned out that way. Religions are having an enormous impact on political events and the search for social justice; and people are turning more and more to religious and spiritual sources for a sense of meaning in areas of life pertaining to bioethics. I suspect that changes in religious ideas will have far more impact on the bioethics of the next period than changes in science.\(^{11}\)

Charles Curran, a very unorthodox Roman Catholic moral philosopher, has proposed a relationship between the institutional church and coercive law that 1) provides as much freedom as possible and as little restraint as possible, 2) will promote justice, public peace, and public morality, and 3) be pragmatic, particularly in matters of enforcement.\(^{12}\)

In *The Story of Bioethics* Engelhart refers to his text *The Foundation of Christian Bioethics*. In that text he refers to Patriarch Bartholomew, the Archbishop of Constantinople


\(^{12}\) Curran 126.
and New Rome, the current head of the Orthodox Church who described a quite different understanding of morality. It is based on:

…the life of first-millennium Christianity, living still. At its core lies a canonical, noetic experience ‘confirmed by grace in the heart [Heb.13:9].’ Those who are willing to recognize the cosmos as the creation of a personal, omniscient, omnipotent God can, through right worship, come to discern in that creation not merely the signs of God but the presence of God. Out of an experience of that God, they can orient themselves in a rightly structured moral understanding, a canonical, content-full morality. This is not the place to say more about this noetic grounding of morality, only to indicate its presence like a door to be opened, through repentance and the response of a personal God. This grounding of substantive morality within rightly oriented worship leading through purification to illumination and union with God discloses a morality quite different from what can be offered either by discursive rationality or free choice.\(^\text{13}\)

\(^{13}\) Engelhart 104-105.
ANTHROPOLOGY

The Role of Physiognomy

Alice Domurat Dreger holds a Ph. D. in the History of Medicine. She has penned an exquisite book entitled One of Us: Conjoined Twins and the Future of Normal examining conjoined twins in a refreshingly new light; as neither freaks nor pitiable. She outlines the predicament of children with unusual anatomies who find themselves the objects of sorrow and pity because of their “cursed, tragic” deformities. But modern medicine “comes to the rescue,” creating normal children free from a life of shame and mockery and able to live a full life otherwise unavailable to them. But they always have to have their anatomy changed to fit the social context.¹ The problem with this scenario as discovered by Professor Dreger in her interviews with multiple conjoined twins is that most people who are conjoined neither feel physically entrapped nor desire a singleton body. They do not perceive of themselves as fundamentally flawed. They view their bodies as normal and acceptable. It is not the fear of surgical separation that influences their choice to remain attached. It is of significant note that the only twins to give consent to their own separation was in 2003 at the age of twenty-nine.² (They were craniopagus conjoined twins who both died intra-operatively secondary to uncontrolled bleeding. She boldly states:

² Dreger 7.
While by no means arguing against all normalizing surgeries, I would like to problematize a process that is too often portrayed as a technological fairytale in which everyone but the dragon called Deformity ends up happily ever after.³

“American culture equates individualism with independence, and interdependence with weakness.” To be truly American, “you must show yourself to be different, separate, distinguishable from all others.”⁴

A mother of conjoined twins opined,

We have to remember that it’s not just a matter of separating them physically, but also psychologically, spiritually, and emotionally. I don’t know that the rest of us really have the capability to make that decision for them.⁵

The mother of one set of craniopagus twins born in 1949 was told by the medical establishment when her daughters were two years old that they would never walk and should be institutionalized. They actually sang and performed on a gospel tour in their teens and

³ Dreger 8.

⁴ Dreger 31-32.

⁵ Dreger 34-35.
died in their own apartment at the age of forty-three years while obtaining associate nursing degrees.

The choice to remain conjoined has huge financial consequences. “…vast sums of money and other resources seem to be available for “normalization” but very little for ongoing support…”

Those children who undergo separation procedures are often referred to by nursing staff and the press as “brave little fighters.” But as Simon Mawer points out in his novel Mendel’s Dwarf “In order to be brave, you have to have a choice.”

The actual decision maker usually lacks first-hand knowledge of the condition, will not personally undergo the procedure, and will not bear the risks nor suffer the costs.

Professor Dreger poignantly asks the questions: “What are the goals of these surgeries? And are those goals likely to be achieved?” She answers her own questions forthrightly:

It is important to set aside the idea that separation surgeries are simply medically necessary procedures. Non-emergency separation surgeries almost never improve the physical health of either twin. In fact, they often leave the children’s bodies – at least temporarily and often permanently – much more ill and impaired than before, and they may significantly reduce life expectancy. While they may look medically necessary in the traditional sense, they are almost always performed primarily for

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6 Dreger 35.

psychological reasons - because the adult decision makers believe the children will be
better off psychosocially if separated, even if this means the children lose function
they would otherwise have…parents choose surgery in the hopes of increasing some
particular function, such as mobility…even these “functional” issues are essentially
psychosocial…Thus, the primary reason for most non-emergency separations is not
physiological; it is not reduction of illness or increase in life expectancy. It is the
desire to make children who have very unusual anatomies look fairly usual, and to
give two children who are supposedly trapped in a single body greater physical
independence, freeing them from the stigma of conjoinment and enabling them to
enjoy, among other things, a “normal” sex life.8

Conjoined twins suffer psychopathology at roughly the same rate as the general
population.9

In a review of the legal proceedings of a 2000 British case ruling on the legal
permissiveness to operate on conjoined twins against the parents’ reasoned wishes George
Annas opined of the appellate judge in an article in the New England Journal of Medicine

8 Dreger 60-61.

entitled “Conjoined Twins” that he (the judge) must hold the supposition that “…being a conjoined twin is a disease and separation is the indicated treatment.”

Professor Dreger makes the emphatic point that “normal” physiognomy is not necessary for full personhood or value.

Christian Anthropology

In the most fully developed phase of medieval thinking, Thomas Aquinas said that, for Beauty to exist, there must not only be due proportion but also integrity (in other words, all things must have all the parts that rightly belong to them and hence a mutilated body is ugly)…

So states Umberto Eco in his The History of Beauty. Until 1500 man was seen primarily in a theological context as a creature of God in the Western Tradition. With the advent of the Renaissance man replaced God as the measure of all things. Both the Protestant Reformation and the Roman Catholic Counter-Reformation were theocentric movements attempting to curtail the secularism spawned by the Renaissance. In the seventeenth century English Deism appeared as a product of the Age of Reason. Man was ripped out of theocratic thought leading to a split of the relationship of God and man. This development of theology led to much unbelief.

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10 Dreger 104.
Calvin addressed man’s relationship to God when he stated that without true knowledge of God you cannot have true knowledge of man. He also affirmed a *sensus divinatus* present in each man (*The Institutes*, Book I, ch. 31, sect. 1). God in His divine counsel elected to create man. Man was materialistic (somatic) from his beginning. There was not a soul that was searching for a body. God breathed life into the man He had formed in His image. This act portrays the sacredness of humankind. This in part explains the death punishment for one who would do violence to a creature of such worth. (Gen. 9:6) Man is put in a position of authority and responsibility for plants and animals and is to multiply as well. The body is inherently good at The Creation, but man now returns to dust as a curse for his sin. “There belongs to man a subsistence or entity distinguished from the body and characterized by qualities of virtue of which it does not undergo the dissolution that befalls the body in death.” (John Murray) The disembodied state is one of continuing personal identity and consciousness, memory, and a sense of bliss and pain.

Ultimately the value of man is tied to the fact that he is made in the image of God. God is the original; man is but a poor copy. In Book I, chapter 15 of *The Institutes*, Calvin writes that the proper image of God is in the soul. He compares “image” to “likeness.” Yet even the body has some glory of God’s image. The woman is the glory of the man and mirrors his glory of being in the image of God. (I Cor. 11:7,8) Eph. 4:24 speaks of the image of God as being defined as knowledge, true righteousness and holiness. Murray states, “The ultimate criterion of obligation to God is likeness to God.” Calvin notes that fallen man’s problem is with moral truth (Book I, chapter 5). The natural man remains “in the dark” as
he chooses to suppress righteousness (Rom. 1:18). Yet his conscience is proof of his obligation. Though fallen, he still has understanding, affection, and relationship. The fallen conscience can be trained by studying the Word and by its experience of discipleship. Motive, the inward ground of someone’s decision or action, must be good or morally indifferent and seek a good act. Man’s intrinsic image was not lost (and is incapable of being lost). The metaphysical – the purity of the ethical - was lost. Dominion was lost; but the drive to creativity partially remains. The body of fallen man is the least reflective aspect of its original image. Morphology or handicap is not grounds for non-qualification of personhood. Scripture does not countenance intellectual capacity as a requisite for personhood.

The importance of the body is seen in the vast number of specific references to individual and group healings as well as generic references to the multitudes coming to Jesus and his healing of them.

**Evolutionary Anthropology**

Current secular/atheistic anthropology is founded upon the evolutionary hypothesis. Its presuppositions, simply put and most commonly promulgated, are that the universe came into existence as part of a “Big Bang” of incredibly dense matter 15-20 billion years ago, that the earth came into existence 1.5-5 billion years ago, and life forms developed from simple elements several hundred million years ago. Hominid forms evolved 100,000 years ago. Earliest “man“ was 30,000 years ago. These numbers are certainly arbitrary but
generally make a gestalt representation. In this model without divine intervention or intelligent design man is a random occurrence without purpose. The value of such a development is purely arbitrary. If you admire complexity, “man” is worthy of value. The concept of “the survival of the fittest” connoted that the survival of the strongest, fastest, or other attribute to avoid predators as the primary construct of evolution is a malapropism. The chief factor was simply specie reproduction in excess of specie consumption. The value of man as compared to plant or other animal life is simply arbitrary. Still many atheists hold to the concept that life is “precious.” (Professor Patrick Grim, “Questions of Value,” 25)

Some ecology awareness and animal rights groups recognize this fact openly. Although amoral science holds this view, medicine, based on science, cannot dissociate itself from its foundation as a profession practicing an art that holds human life to be of substantive value. Still, it cannot appeal to science to support its viewpoint.

So where are we with respect to anthropology and medicine? The German M. Scheler stated in his *Die Stellung des Menschen in Kosmos* the following:

In no other period of human knowledge has man ever become more problematic to himself than in our own day; we have a scientific, a philosophical, and a theological anthropology that know nothing of each other. Therefore, we no longer possess any clear and consistent idea of man. The ever-growing multiplicity of sciences that are
engaged in the study of man has much more confused and obscured than elucidated our concept of man.\textsuperscript{12}

He penned those words in 1928, nearly eighty years ago. How much more is the confusion and obscuration today?

CHURCH HISTORY AND MEDICINE

The earliest church was authenticated by its “signs and wonders” and specific instances of healing. As Western medicine had little to offer of scientific substance until the 1800’s with the introduction of anesthesia and the concept of asepsis, one’s prognosis was simply at the providence of God. It was often assumed that physical affliction was also the work of God. Thus the priest was also often “shaman” as well. With biblical examples of care for the infirm as required of those more fortunate, it was the church that founded the initial hospitals with the development of urban centers in the Middle Ages. Roman Catholic, Protestant, and Jewish hospitals were the primary extenders of care late into the twentieth century when so-called “for profit” hospital corporations entered the health industry with a profit motive rather than an eleemosynary goal as their raison d’etre. The “religious” hospitals often forsook their roots in order to “level the playing field” of financial competition and appeal to a broader community base.

The Enlightenment provided the philosophy and the science of the last 200 years as the foundation to rend medicine from the domain of the priest and place it in the hands of an elite guild. This trade functioned under the apprenticeship model and continues to do so to this day. Only in the last half century have both its paternalistic attitude and its “cottage industry” economics been challenged.

Medicine in the United States now represents 12% of the gross national product. Physicians’ compensation is less than 10% of that total, but they direct nearly 70% of the
dollars spent. Government, insurance companies and hospital conglomerates are the major players. The institutional church is largely a disinterested spectator with only its names on the buildings to reveal its past relationship.
J. B. A. O’Connell published an article in the British Journal of Surgery, 1968, Vol. 55, No. 11, November, entitled “An Operation to Separate Craniopagus Twins.” As to the timing of the separation, he suggests between nine and twelve months because their physical handicap begins to impair their mental development at that age. No source or reference is given for this observation of developmental psychology. By that time nursing staff have also became aware of differences in the children’s personalities further indicating the babies were distinct individuals.

Dr. O’Connell addressed the ethical dimension of the problem with all of the reasoned deliberation expected of a British surgeon of the pre-formal bioethical age:

The answer to the ethical question of whether or not separation should be attempted will be based on the views of those concerned, both the parents and their medical advisors. When observation reveals the twins are separate individuals capable of long survival, it is probable that few surgeons would deny them a chance of normal life. Even should investigation reveal abnormalities, which would make the attempt at separation hazardous and the possibility of saving both children remote, many would consider it justified.¹

No grounds of such justification are offered.

Dr. O’Connell describes the four technical problems encountered in this surgery that remain the cornerstones of pre-operative evaluation still today. They are 1) the preservation of the coverings of the brain – both the dura mater and skin, 2) the limitation of bone removal, 3) the maintenance of venous drainage (“at least for one child”), and 4) the separation of the brains of the two children.

During the course of the separation of the twins he describes (a three-stage procedure was performed) twin B died intra-operatively. The surviving twin A had a long bout of meningitis that resolved without sequelae but did have a permanent “left hemiparesis of moderate degree.” A large cranial defect requires the patient to wear a protective plastic hat.

In his denouement Dr. O’Connell notes that it is imperative to preserve venous drainage and that “usually such drainage can be achieved only in the case of one child.” He then asks “Is it permissible to sacrifice the life of one twin in the hope of providing the other with an opportunity of normal living?”

The concept of conjoined twins as “freaks” has a long history in the medical literature. The opening paragraph of an article from the Journal of Neurology, Neurosurgery, and Psychiatry, in 1974, has this inclusion:

…conjoined twins have been the object of curiosity to laymen and doctors alike.

Mankind has fortunately progressed from looking upon these children as monsters to a more constructive concern with practical management of the disorder.²

In 2002 the *Journal of Neurosurgery* had an article whose opening sentence of the abstract read “*Siamese* (italics mine) or conjoined twins have intrigued both the physician and layperson for centuries.”³ In 2006 an abstract of a review article in *Brain* on the craniopagus malformation begins “Craniopagus twins (CPT) are an uncommon, highly fascinating *accident of nature* [italics mine].”⁴

The pre-operative assessment has advanced exponentially over the last thirty-five years. The “Comments” section of *The Medical Journal of Australia* of April 3, 1976, was introduced using the byline “Successful Separation of Craniopagus Twins” alluding to a successful surgery performed in Paris, France, July 22, 1974, after acknowledging two successful separations of conjoined twins (not craniopagus) separated in Melbourne, Australia, in the last several months. The decision to separate the craniopagus twins was based on the appraisal of a pediatrician who “considered that the children were mentally viable.” No mention of a radiological evaluation was recorded. By 1979 the first article was published describing the value of computed tomography (CT) in the evaluation of craniopagus twins. Simulated plastic models have been available since the mid-80’s

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allowing a three-dimensional tactile replica of the patient.\textsuperscript{5} The literature is now replete with articles advocating CT with and without angiography, magnetic resonance imaging (MRI) with and without angiography, and cerebral angiography. The use of frameless stereotaxy was employed in Toronto in 1995\textsuperscript{6} (and employed in the case under discussion). An article in the \textit{Journal of Neurosurgery} dated October 1998, advocated the additional advantage of intra-arterial digital subtraction to provide data unobtainable by “standard” imaging.\textsuperscript{7} The value of scintigraphic evaluation of craniopagus twins using radionucleotides to image the brain, liver, kidneys, and heart was also presented in 1998 from South Africa to rule out other anomalies and evaluate brain function.\textsuperscript{8}

Pre-separation procedures have also advanced over time. The use of tissue expanders has become routine in some situations. Intra-operatively, cardio-pulmonary bypass and

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hypothermic arrest was utilized once in what was considered to be an otherwise inoperable situation in the 1980’s without a positive outcome.⁹

Case Reports solely on the management of anesthesia were published by the Singaporean and Chinese teams in 2003 and 2004, respectively. Prior to this time, the anesthesia management had been reported within the body of surgical articles.

An overview of the chronology of published cases involving the separation of craniopagus twins reveals the successful separation of twins in South Africa in 1968 with cerebral angiogram and air encephalogram as the only neuro-imaging modalities employed. Central venous catheters were placed but “arterial cannulation was not considered practicable by the surgical team.”¹⁰

Dr. Giulio Gaist et al. published a review paper describing their unsuccessful attempt to separate craniopagus twins (both died) in 1987. They proposed a new classification system, utilizing surface of junction, brain deformities, and vascular venous connections as parameters. They make a poignant presupposition:

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When dealing with a case of craniopagus twins, the main problem is the feasibility of surgical treatment. Successful separation is certainly possible and, therefore, mandatory (italics mine) in partial and in some intermediate (subtype a) forms.\textsuperscript{11}

They note a case of conjoined twins who were not separated at birth who …had sufficiently adapted in adulthood to their infirmity, they nevertheless showed gross mental retardation and severe limitations in their everyday life. In our opinion, the pitiful quality of life for cases not operated upon and their condition, which is indeed the “appalling bondage” as O’Conner called it, makes every attempt at surgical separation not only justifiable but also humanitarian.\textsuperscript{12}

The twins they describe are reported by A. B. Todorov et al. These children, cared for at home, managed to get the equivalent of high school diplomas through a local tutorial system. They toured in circuses and as gospel-singers. Todorov describes the girls as having “Intellectual potentials in the low-average range…Educational [italics mine] retardation was gross.” Those phrases hardly correspond with Gaist’s “gross mental retardation” quoted above. Dreger tells us they were attending nurse’s aid classes when they unexpectedly died


\textsuperscript{12} Gaist et al. 331.
at age 43 and living independently. As for O’Conner’s “appalling bondage,” they did not wish to be separated as a humanitarian act or under any other pretense. Todorov’s report in 1987 includes that of 14 cases he reviewed, only eleven of the twenty-eight children survived and only seven were intellectually normal (one in four of the total number operated upon).

The same year as Gaist’s report was published (1987) Drs. Bucholz, Yoon, and Shively also published a case report and review of the literature. They used a three-staged procedure but had severe bleeding leading to hypotension to which they attribute the severe developmental delay of one twin. Their chart of previous outcomes since 1960 showed that only those twins with no venous interruption had normal outcomes. The one exception was their own patient. Of 25 patients, twelve died, two had a severe neurological deficit, five had a focal deficit, and six were normal. Their key points of data were that those twins with shared neural tissue were at highest risk for profound neurological deficits; the extent of venous connections at the junction site remains an extremely important determinant of operative mortality and morbidity; and that craniopagus twins who have been separated in stages uniformly did better than those separated at one-step procedures and have had a significant decline in operative mortality.

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13 Dreger 35.

14 Todorov et al. Table 2, 1296.

The timing of separation in elective cases has leaned toward at least the latter part of the first year of life for physiological reasons. A paper describing the separation of conjoined twins of all types from Cape Town, S. A., in 1997 remarks “It is generally regarded that the longer the twins are attached, the more the personal identity may be lost. Therefore, separation should certainly be considered under 1 year of age.”  

A case report describing the surgical risks of separating craniopagus twins joined at the occiput in 1997 gave the following statistics: 33% chance both might die, 33% chance that only one would die, and 33% chance both would survive. There was no mention of percentages regarding morbidity.

In 2004 Dr. Scott Campbell et al described their second opportunity to separate craniopagus twins in Brisbane, Australia. Even with their experience, they write “No one hospital or center in the world has significant experience with the surgical separation of craniopagi.” In their “Conclusions” I have selected two remarks:

3) There are ethical and potential legal problems if operative separation causes the death of one or both individuals who are relatively intact in the conjoined state…

5) Prior to surgery it is essential to seek consultation. It is important to include

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ethical and legal consultations.\textsuperscript{18}

Campbell was the single author of a more reflective paper published online one month later. He amplified an earlier observation:

Given the rarity of craniopagus and the high level of expertise that exists at individual centres around the world, it is likely that most cases will be operated upon locally by surgeons with little or no experience…Therefore, as stated by Winston et al. in 1987, operating with lack of experience cannot be criticized, as long as the surgical team has meticulously prepared, consulted widely and has modern resources available at their hospital for appropriate preoperative investigations and postoperative care.\textsuperscript{19}

He quotes O’Connell indirectly, saying, “O’Connell noted that with craniopagus twins, there is no chance of a normal life whilst they remain connected, so separation is a reasonable proposition if there is a chance of success.”\textsuperscript{20} Campbell adds, “It can then mostly be assumed that if the parents elect to go ahead with the pregnancy, they do so with a view to surgical separation after birth if possible.”\textsuperscript{21} He also astutely notes that

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\item \textsuperscript{18}Campbell, S. et al., \textit{second Brisbaine} 524
\item \textsuperscript{20}Campbell, \textit{Brisbaine} 602.
\item \textsuperscript{21}Campbell, \textit{Brisbaine} 602.
\end{itemize}
“Conjoined twins have always attracted intense media interest, particularly those joined at the head, which adds to the pressure of separation.” While espousing a staged separation, he notes a trend toward single stage separation procedures.

The online publication of the experience of the UCLA separation of craniopagus twins from Guatemala leaves an indeterminate estimate of the girls’ outcomes. Twin A is recovering from *E. Coli* meningitis that caused severe motor and cognitive impairment. (The fact that the meningitis was directly related to the placement of a ventriculoperitoneal shunt made necessary secondary to an intracerebral hematoma, which was a complication of the surgery, somehow gets lost.) Twin B required a “vigorous” rehabilitation program. She is now thriving and “showing clear evidence that allows us to substantiate our hope that twin B will lead a normal life.” That does not have the same nuance as saying that she is now normal. This was a one-stage procedure lasting 15 hours.

An article from the Netherlands published online in July 2004, reports a work-up of craniopagus twins that revealed they could not be separated with “a fair chance of survival.” The parents elected not to have the twins separated.

Drs. Marion Walker and Samuel R. Browd of Salt Lake City, Utah, concur with previous authors that separation of shared blood supply is the most critical aspect of the

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22 Campbell, Brisbane 603.


procedure. Their report in 2004 published online in July supported the ratio of female: male of 4:1 reported in earlier reports but differed from an article in *Teratology* in 1982 which reported conjoining to be more common in nonwhites than whites contra the Utah report that claims no racial predilection. They support the staged separation protocol.²⁵

Dr. Goh wrote a case report published online in July 2004, about the separation of craniopagus twins in Singapore. One survived with minor disabilities, the other with severe developmental delays. The surgery is noteworthy for its greater than 100 hours duration.²⁶

Drs. Goodrich and Staffenberg are vocal proponents of the staged approach protocol. In their view, “…the most important benefit of the staged procedure is that it allows the bridging veins to be divided sequentially, thereby promoting the improvement of collateral venous drainage.”²⁷ The twins they report separating are receiving speech, feeding, occupational, and physical therapy. “No detectable neurological deficits were reported by the authors’ neurology colleagues who received them.”²⁸ And yet they are receiving four types of therapy. Dr. Goodrich has joined rank with Dr. James Stone of Chicago to create a new classification system for craniopagus twins published in *Brain* in 2005. It reveals most


²⁸ Staffenberg 34.
tellingly the lack of follow up documenting the extent of neurological injury these patients sustain. They treat “mild-moderate or normal outcome” as a single category and “severe disability” as the only other survivor category.\textsuperscript{29} (Surely moderate disability is not the same as normal.)

On the same day that the Egyptian twins were separated in Dallas, a surgical team in Rome completed the staged separation of craniopagus twins without mass media pressure. They utilized a little misdirection in order to honor the parents’ request for privacy. They held their first press conference three days after the surgery.\textsuperscript{30} (Obviously the surgical participants were not seeking media attention.)

From a technical point of view, the Dallas surgery was a huge success. A single staged operation was performed. Neither twin was sacrificed. Only one required cerebrospinal fluid shunting. Neither suffered more paresis than expected nor had speech impairment beyond expectations. The outcome matched what the ethics committees were informed would likely happen if things went well. A special table was developed as well as custom head holders.


THE MEDICAL TASK OF SEPARATING CRANIOPAGUS TWINS

The first order of the day is to get as much imaging data as possible to determine the feasibility of separation surgery and, if feasible, to determine an operative plan that will likely lead to a successful separation.

The sophistication of imaging devices is simply mind-boggling. All of these patients undergo computerized tomography (CT) and magnetic resonance imaging (MRI). Most undergo MRI angiography and cerebral angiography. Some investigators advocate digital subtraction angiography as a valuable study.\(^1\) Others utilize functional MRI. With rare exceptions these studies require the provision of general anesthesia for both twins. The physical configuration of these machines makes the imaging of “two” patients simultaneously problematic. The availability of more than one anesthesia machine compatible with the MRI magnet is rare. Even experienced expert interventional radiologists are challenged by these patients. The less adept are overwhelmed leading to inadequate or insufficient studies at the expense of professional time and equipment and anesthesia risk to the patients. From these studies 3-D CT’s can be constructed and plastic polymer models created to aid the surgical teams in visualizing potential surgical planes of approach.\(^2\)

Scintigraphic studies with radionuclotides are valuable in assessing other organ system


anomalies associated with conjoined twins. Echocardiography is routine in these patients. Stereotaxic studies are performed to guide the surgeons intra-operatively. The use of embolic techniques by interventional radiologists has been a very reasonable and proven pre-operative approach in selected patients.

The anesthesia challenges are multiple, both for the simple number of times the twins must undergo anesthesia for imaging studies and surgeries preparatory to the actual separation such as insertion and expansion of tissue expanders. Each child requires its own anesthesiologist and many centers utilize an additional coordinating anesthesiologist as well. Issues of intubation, central line and arterial line placement, temperature control, volume maintenance, and blood product replacement are often technically difficult. Early anesthetics determine the extent to which blood mixing (and therefore anesthetics) occurs between the twins. As the final separation requires a circumferential incision of the head, positioning during surgery is dynamic rather than static. The development of a single bed with the

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5 Rutka et al., 587-592.
capability of rotating on its long axis and separating into two individual beds when the
separation is complete was utilized for the first time in the case which this paper addresses.6

Laboratory support and especially blood bank capability require that these procedures
be performed at tertiary pediatric centers.

Most cases of separation of craniopagus twins are reported in the medical journal
literature. Those that are not have usually been those with death or severe neurological
damage as their outcome. Long-term follow-up is usually lacking. The surgeons involved
with the cases usually communicate with others who have undertaken the procedure before in
order to enlarge the knowledge pool. Both neurosurgeons and plastic surgeons with
experience in cranio-facial procedures participate in these events.

Conjoined (Siamese) twins occur approximately once in 50,000 live births and
craniopagus twins once in 2.5 million births, only a handful per year worldwide. There are
many variables to be assessed with each set of craniopagus twins. First, other anomalies that
will affect long-term survival must be identified. Secondly, the angle at which the heads are
connected is significant. Thirdly, the amount of brain tissue that is shared is a prognosticator.
Fourth, the capability to provide both tissue and bony coverage of the brain after separation is
penultimate. Lastly, and most importantly, is the presence or absence of certain venous
structures and the intracerebral venous drainage of one twin to the other.

6 Swift, Dale et al., “Total vertex craniopagus with crossed venous drainage: case report of
Usually the brains are not separated by bone but are by dura (the tissue normally loosely covering the brain), but then only one dura is usually found. The brains may interdigitate, be compressed on one hemisphere, or even wrap each other in a helical fashion. Each of these variables has its own problems at separation. O’Connell first proposed a classification system to describe the various relationships of the heads and their contents to each other in 1968. Bucholz reported on a case and proposed a second classification scheme in 1987. Even within the rarity of this clinical entity there are multiple presentations. His classification scheme was correlated with clinical outcome. This provided information that could be utilized in obtaining informed consent.

The advantages of tissue expanders and fascia lata grafts for tissue coverage of the brains after separation have been well reported and are routine when indicated.

The primary arena of debate in the management of these patients is that of performing a single separation surgery or utilizing staged operations culminating in a separation of diminished magnitude.
ETHICAL ANALYSIS OF THE CASE

Within a few months after birth it was evident that the Egyptian twins did not have any life-threatening anomalies and that surgical separation could be considered. Imaging studies were of such a poor quality in Cairo (the first attempts at imaging in Dallas were also unsatisfactory) that copies sent to centers for evaluation of the twins yielded limited data. At least a half a dozen centers were contacted. One had separated one set of craniopagus twins, another none. One surgeon had been successful in one country but failed miserably in his next attempt in a different country (U.S.A.). Some centers welcomed the opportunity to evaluate the children and perform surgery, if deemed feasible, but required substantial financial expenditures be born by the twins’ family or country’s health service. As mentioned earlier, a pediatric surgeon who had observed craniofacial surgery in Dallas for many months contacted a well-recognized cranio-facial surgeon in Dallas who promised free evaluation, hospitalization, and surgery, if feasible. Neither this surgeon, nor any surgeons later involved in the separation surgery, had participated in cranial separation surgery before. The decision of the twins’ parents, rural folk of limited education and financial resources, with the medical caretakers’ urging, settled on both the pecuniary advantages and a known personality appeal rather than the experience of the medical team or hospital.

Issues of both medical team and hospital leadership were a continuous work in progress. The children were hospitalized at Hospital 1 where the cranio-facial surgeon (Dr. A) practiced, had their initial work-up in Hospital 1. They were transported to Hospital 2 for
better imaging and interpretation. The chief neurosurgeon (Dr. B) practiced primarily at Hospital 2. Since the operative procedure is *primarily* (italics mine) a neurosurgical one and the neurosurgeons practiced primarily at Hospital 2, the neurosurgical team insisted that the surgery be done at the pediatric hospital with which they were most comfortable, offered (in their opinion) the best operative support system, and have the administration and public relations department of Hospital 2 handle media relations to their liking. They perceived “their liking” to be significantly different from that of Dr. A and Hospital 1.

Both Dr. A and his associates and Dr. B and his associates met with the Ethics Committees of both hospitals. Hospital 1’s Ethics Committee has no members formally trained in ethics. Hospital 2’s Ethics Committee does have a member who is both a professor of law and well versed in medical ethics. The information provided to the Ethics Committees of both hospitals were the same. Mention was made of the timing of surgery in the sense that further delay would make personal identity more difficult for each twin to resolve at separation. The committees were told that there was a 15-25% chance that one or both of the twins would die or suffer severe neurological insult. They were told that they would not sacrifice one twin on the other’s behalf. They were not told that one interventional radiologist did not think it possible to separate the twins without significant neurological damage to one twin and that sacrificing one for the other would lead to a better result in the survivor than if an attempt to preserve both of them were made. In spite of the fact that no member of the proposed surgical team had participated in the separation of craniopagus twins, the surgery was not couched in terms of “experimental” surgery that requires
additional ethical issues to be considered. The committees were told that if the surgery were successful, both twins would each have unilateral motor weakness and probable speech difficulty. Speech, occupational, and physical therapy would be expected to ameliorate the extent of neurological compromise over time. This is as close to “normal” as could be expected. Both Ethics Committees approved of the planned procedure.

Informed Consent

The surgical team had consulted extensively with other surgeons who had performed this surgery, both successfully and unsuccessfully. But can one really provide informed consent for a surgical procedure you have never performed or witnessed?

In the case of children, informed consent is provided by surrogates. These are usually the parents. Those providing informed consent followed the recommendations of the bioethicist Edward Pellegrino and took into account the twins’ parents’ culture, country, religion and experiences to provide them a framework to make an informed decision. An imam in Egypt and one in Dallas stated that separation surgery was permissible. The father was concerned about the boys’ virility following surgery. He was informed it would not be affected by the surgery. But in the best of situations regarding the impartation of understanding of what this surgery was comprised, do the parents (in this instance, because of the culture, particularly the father) have the ability to understand, deliberate, and decide on the information presented? Is decisional capacity present?
Having come so far in terms of time, distance, medical assessment, and financial expenditure, is consent in this context truly voluntary; or, is there a sense of coercion because the medical “train” is so far down the “tracks?” Is this consent truly voluntary?

In terms of disclosure the surgical team followed the professional practice standard and “reasonable person” standard as well as the subjective standard.

They also made a recommendation (for separation) as to the best plan of action.

In the element of understanding necessary for informed consent, the risks and consequences, the benefits, the probability of success, and the prognosis if therapy is not given, must be comprehended by the surrogate. If the current literature referenced above is accurate, should the risk of death or severe neurological insult be communicated as being 15-25% when the collected data indicates it is closer to 60-70%? One person on the neurosurgery team told one member of the anesthesia team the night before surgery he thought there was an 85-90% chance of death or severe neurological insult occurring in one or both boys (private communication). Many of the nurses of Hospital 1 cried as the twins left for Hospital 2 for the surgery because they did not expect both of them to return alive.

The medical team felt it had provided all the information necessary for the family to make an informed consent and to exercise autonomy in this matter. The medical team opined that the risk: benefit ratio was acceptable. The creation of two separate twins with independent ambulation, unilateral neurological weakness, and speech impairment was clearly better than two healthy twins attached at the cranium in rural Islamic Egypt.
Imams, doctors, hospitals, and the media are in agreement as to the need for surgery confirming the observation of the Rothmans that “the most influential voices coming from science, medicine, culture, and commerce are likely to emphasize potential benefits and discount the dangers.”

The family decided to go forward with the surgery and authorized the consent.

The Looking Glass of W. D. Ross

It was mentioned earlier in this paper that W. D. Ross proposed an ethic that not only looked at acts but the motives behind them. The most commendable scenario was a right action from a right motive.

In our case the team of Dr. B suspected Dr. A of exploiting the twins to raise public awareness of his medical practice and of a foundation which he created that directly benefits his practice. Dr. A accompanied the twins on the afternoon television host tour (including Oprah Winfrey) presenting himself as the overall leader of the medical team. Dr. A was particularly hopeful that the twins could be separated in time to make the 6 p.m. national news outlets. One of the reasons Dr. B insisted on performing the surgery at Hospital 2 was so that the staff at Hospital 2 could control communication with the media.

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Each of the hospitals involved were getting good press. Both undertook huge financial losses by providing the care they respectively provided. Hospital 2 asked for $100,000 to be raised in support of the twin’s separation. The local Muslim population responded and gave the amount asked, but no more. Hospital 2 is the recipient of as much as 30% of the community’s yearly eleemosynary largess. As Hospital 2’s expenditures may have easily exceeded $1,500,000, the request for such a small amount of the actual cost appears ill advised and niggardly. Both hospitals benefited from a public relations standpoint.

Social Justice

The total amount of U.S. dollars necessary to bring the twins to the U.S., evaluate them, perform the surgery, rehabilitate them, and send them home is estimated to be a value that exceeds $6,000,000. In a world of limited resources, is this expenditure reasonable to separate craniopagus twins with the surgical risks published in journals internationally? For one thing, time and services in kind provided to the twins are not available to be applied to another medical venture. People who volunteered their time for this endeavor may choose not to donate that same amount of time for any other endeavor. Secondly, as Prof. Dreger pointed out, coffers open for surgical separation, but not necessarily so for those who choose not to separate who still need unobtainable resources. Some use the N.A.S.A. rationale that the benefits of successfully completing such a procedure adds to the total armamentarium of surgical possibilities and therefore more will be benefited in the future, not simply the twins
who are separated. Americans aware of children denied operations for financial reasons ask why these foreigners are chosen to receive what they cannot obtain. Perhaps 1,200 children could undergo cleft lip or palate repair in third world countries for the same price tag with a cumulative operative risk less than or equal to the risks of the twins’ separation. Nutrition, speech, and social acceptance would be dramatically improved as compared to independent ambulation and social acceptance in the case of the twins.

The Christian ethical paradigm has spoken loudly in the public arena for social justice in recent decades. Widows, orphans, and the oppressed and less fortunate are to be cared for according to Scripture. In the Old Testament period, the Mosaic law forbade those with physical defects to enter the temple court for men. The New Testament contains the Parable of the Good Samaritan. Here a man cares for a man of an inimical race needing acute medical attention and ignored by his own kind. The Samaritan gives of his time and his fortune immediately and makes promise for the future. The Samaritan is held up as the model of a neighbor. The Ether Statue of Boston, recently restored, commemorates this story. The new commandment given to the apostles on the night of the Last Supper was to “love one another.” As for performing mercy ministry, Christ proclaimed, “if you have done it unto the least of these, my brethren, you have done it unto me.” Therefore the desire to please Christ out of love will be manifested by works of mercy to the needful.
Summary

In summary, reasons not to participate in the separation included the following:

1. The benefit did not clearly outweigh the risk, especially the potential harm.
2. True autonomy was tenuous at best, and the informed consent can be easily interpreted as misleading.
3. An enormous cost is incurred for an uncertain outcome. Social justice is ignored.
4. Referencing W. D. Ross, some motives are questionable, some actions are suspect.
5. The amount of pro bono time is prohibitive for an uncertain task.

However, a yearning to participate is fostered by the virtues of compassion, charity, and wisdom. The Divine Command ethic as gleaned from The Parable of the Good Samaritan has much to commend itself as to the object of such mercy, active participation, absorption of medical costs, and continued care. The Old Testament requirement for physical integrity also could be cited for support of the separation endeavor. However, the risks of harm or death in the light of the sanctity of life precept can be appealed to as justification for not participating.
THE ETHICS COMMITTEE

Hospital Ethics Committees are usually composed of a dozen or so members representing several aspects of the medical and lay community. The hospital’s legal department usually has a representative. If the hospital is part of a university system, a professional ethicist is usually a member. Nursing staff, frequently administrative, is represented. A hospital administrator is normally included. Someone from the hospital chaplaincy is always included and frequently an ordained person from the community is involved. Some committees are likely to assure that Jewish and Muslim faiths are represented. There are several physician representatives. The specialties of hematology/oncology, intensive care and neonatology are commonly involved because of the significant morbidity and mortality inherent in their services. A surgeon and, occasionally, an anesthesiologist represent the surgical staff. It is not uncommon to have Social Services or a state health department representative. One or two lay members of the community are recruited to broaden the perspective of the committee and are supporters of the hospital in some fashion (volunteer work, philanthropy) or have experienced a relationship with the hospital involving a family member and show their appreciation by serving on the committee. Most lack formal educational training in clinical ethics. Members who possess the skills of communication and facilitation and whose intellectual skills include a basic understanding of ethical theories, principles and codes; methods of case analysis and a facility for logical analysis and reasoning are best equipped to serve.
A personal communication of a draft of a chapter of a book on medical ethics addressing the leadership and membership of the committee makes several observations and recommendations. The chair is the de facto face of the committee. He should be energetic and committed, someone who possesses respect and credibility and is a physician in order to obtain credibility with physicians. While this author applauds a multidisciplinary membership, he cautions the inclusion of lawyers, hospital administrators and chaplains.

The Ethics Committee strives to achieve a consensus on its recommendations. Yet a standard philosophical “grid” is not assumed and pluralistic casuistry is the usual order of the day. Deontology is objectively limited to state legal statutes. Nonetheless, the debate is subjectively shaped by Kantian presuppositions. Among those without a background in formal ethical training, comments are frequently prefaced with the phrase “I feel that…” without offering a grounding for their feeling.

Through an obscure gestalt process the four “pillars” of medical ethics are all considered, but usually one triumphs as the primary consideration and is the ultimate hinge on which a decision swings. Facts having to deal with that particular aspect are given the greatest value. It is a subjective process.

When theological issues are paramount in a patient’s case, the members who privately espouse a worldview inclusive of the divine are often schizophrenic. They experience compunction to be obedient to the politically correct, empirical and natural philosophies that dominate their academic and professional worlds. What they will share in
the hallway privately is often considerably different from the muted or sterile intercourse of the boardroom.

Some observers have reported that men are more likely to be deontologists and women consequentialists. If this is true, gender make up of the committee will be somewhat determinant of recommendations.
THE HOSPITAL CHAPLAIN

The personal communication alluded to earlier has this to say about chaplains:

Chaplain membership can be a sensitive matter as well. The specific religious and value system that a chaplain or local minister brings to the institution may not be broadly representative, and a dogmatic preacher can tie a committee in knots. On the other hand, most hospital chaplains are broadly ecumenical and highly skilled at ethical reasoning. In any case, chaplains are front-line caregivers who quickly become involved in the ethical struggles of the patients to whom they are ministering. As such, they can be valuable members, or at least allies, of the committee.

Membership on the committee may also broaden their knowledge and sophistication about ethical views…it is an unfortunate fact that committees tend to defer to a lawyer’s pronouncement about the law, an administrator’s assessment of possibilities, and a clergyman’s vision of what is appropriate.

The Ethics Committee is composed of atheists who view the presence of a Protestant hospital chaplain as an ethicist or an acquiescence to primitive views held by the uneducated, and theists who view him as the purveyor of the wisdom of Western Civilization or servant of the truly Divine. He must have a solid grounding in ethics in general and acquire a foundation in medical ethics if it is lacking. He must be able to articulate a Christian anthropology and defend it apologetically. He must respectfully but definitively dismiss
evolutionary claims using empirical, rational, and biblical arguments when necessary. He must have a requisite knowledge of comparative religions and know the issues that commonly occur in the hospital setting (e.g., blood transfusion and Jehovah’s Witnesses, use of medication and Christian Scientists). Such a fund of information levels the “playing field” and earns a sense of gravitas.

To have an influence beyond the bedside of individual patients and into the making of the milieu of the hospital culture, he should seek appointment to the hospital’s Ethics Committee (if not automatically appointed due to his position in the hospital). He should seek to participate in the education of medical students in their course study of Medical Ethics now required at almost all medical schools. Here he has an opportunity to shape future physicians’ attitudes and professional demeanor before they become jaded and hardened. He must countenance other opinions and ideas in the arena of academia; but he must also follow Peter’s command to be ready at all times with a worthy defense of the biblical position. How much rejection might he expect? An excerpt from a textbook in use in the United Kingdom may reveal some bias:

Religious dogma has continued to act as a potent source of moral direction even up to the present day. This is of course (sic) completely non-sensical: it is stifling to any debate…”

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THE CHALLENGE

The hospital chaplain or physician holding the Reformed tenets of faith is faced with a dearth of modern scholarship with which to be guided. Mainstream journals of medical bioethics are almost void of analyses from a Reformed position. Certain Roman Catholic bioethicists who use Scripture foundationally and moral theology and church history in a supplemental fashion are carrying the torch for the moment in the search for revelatory guidance with which to enter and engage the contemporary library of bio-scientific ideas. One of the ways in which a physician displays genuine compassion is by a continual assimilation of knowledge in the medical world in order to be equipped for his patients’ care. This must be tempered with a deep understanding of biblical anthropology. Only then may one practice his profession to the glory of God. We must articulate and defend our position clearly and unashamedly in the marketplace of ideas.
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