III. MORAL AND RELIGIOUS PERSPECTIVES

MORAL PERSPECTIVES

(NBAC staff are in the process of commissioning a paper on these issues)

- *moral status of bodies and their parts*
- *harms to individuals*
- *privacy*
- *wrongs*
- *group harms*

RELIGIOUS PERSPECTIVES[1]

The retrieval and use of human tissue samples in diagnostic, therapeutic, research, and educational purposes represents a further development in scientific study of the human body as a source of medical information. Since religious discussion of human organs and tissues has largely focused on *donation for therapeutic* purposes ("donation paradigm"), there is very little direct religious discussion of *non-therapeutic research* uses of human tissue. It is possible, however, to describe implications and suggest inferences by considering: (1) religious attitudes to the human body and to organs, tissues, and cells removed from the body; and (2) religious discussion of modes of transfer of body parts, such as donations, offerings, sales, and abandonment.

The Body: Religious Holism, Scientific Reductionism, Private Property

The human body as an organic totality has long been the subject of theological reflection and a symbol of religious communities. However, much less attention has been devoted to the religious status of organs, tissues, cells, and DNA. The reflection of religious scholars and communities on the status of body parts has been prompted by the necessity to confront practical questions in personal and public health and in communal life, such as justifications for surgery, autopsies, organ donation, or burial. Scientific and research interest in *parts* of the body can

[1] This text is derived from Courtney Campbell's paper, *Religion and Tissue Samples*(working title), commissioned by the National Bioethics Advisory Commission.

sometimes conflict with religious values about *bodily integrity*. Indeed, E. Richard Gold cites the "disparate claims of scientific investigation and religious belief on the body" as the exemplary case of incommensurate values regarding the body. According to Gold, "The body, from a scientific viewpoint, is a source of knowledge of physical development, aging, and disease. From a religious perspective, the body is understood as a sacred object, being created in the image of God. . . The scientist values the body instrumentally, as a means to acquire knowledge; the believer values the body intrinsically, for being an image of God." [1]

Theological holism is thus posed in fundamental conflict with scientific reductionism. In the Western faith traditions (primarily Judaism, Christianity, and Islam), theological holism takes as its starting part an assessment about the body in its organic totality and in its fundamental integration with the person. This assessment is perhaps best characterized as an expression of "awe" or "reverence" towards the person, who is portrayed as an embodied self in the "image of God" (*imago Dei*).[2] This understanding entails that the body is intrinsic to personal identity and is invested with an aura of sacrality: the metaphors of "temple," "sacrament," "tabernacle," "sanctuary," are prominent in religious language about the body. This profound commitment to the inherent value of the body is acknowledged, even when, as upon death, the self-body interrelationship is severed. The religious traditions of the west nonetheless require respectful treatment and disposal of the corpse, which in practical terms has often meant a presumption in favor of burial following rituals of remembrance.

Body parts, organs, and tissues can also shape a sense of self. Empirical studies suggest that visible parts of the body, such as skin, genitals, fingers, hands, legs, and eyes, as well as the heart, have a strong correlation with a sense of self. With the exception of the heart, non-visible organs and tissues are not as strongly incorporated into a sense of self. Thus, not all body parts possess equal status, or are equally important to self-identity. Moreover, men and women may value specific organs and tissues differently; males apparently value the liver as part of self-hood, while females place greater emphasis on eyes, hair, skin, and tears.[3] It is possible, as Russell W. Belk suggests, that the less an organ or tissue is connected with a sense of self-identity, the more willing a person will be to donate it for use by others.

By contrast, the dis-integrating body, or a body that is "dis-incorporated" in the sense that tissues or organs have been removed in isolation from the bodily totality may summon a sentiment

not of awe, but revulsion. The emphasis on bodily integrity in the western religious faiths has culminated in the development of stigmas and taboos regarding certain bodily tissues when they are external rather than internal to the body. Characteristically, the dis-incorporation of bodily tissues is assessed by religious thought with reference to issues of purity and cleanliness. A very prominent historical illustration of this issue of purity, which has permeated secular culture and has not been entirely overcome in contemporary religious communities, are stigmas and taboos surrounding menstruation.[4]

This distinction between the status of organs, tissues, and fluids when they reside in and are integrated within the body rather than outside and separate from the body is displayed as well in an illustration by Gordon Allport: "Think first of swallowing the saliva in your mouth, or do so. Then imagine expectorating it into a tumbler and drinking it! What seemed natural and 'mine' suddenly becomes disgusting and alien. ... What I perceive as separate from my body becomes, in the twinkling of an eye, cold and foreign." [5]

There are then different ways of assessing the theological and moral status of the body and of body organs and tissues depending on the "place" of the organs or tissues, that is (1) intrinsic to self-identity (e.g., heart) or incidental; (2) visible (eyes, skin) or hidden (kidney); and (3) integrated (circulating blood) or dis-incorporated (bodily excretions). In general, it may be claimed that the more an organ, tissue, or fluid possesses the former of these characteristics, the more its retrieval and use for biomedical research purposes may present theological and ethical questions. Put another way, Western religious thought on the body begins with a strong presumption that the status of the body as a whole is greater than the sum of its parts. Body organs and tissues, moreover, contain potent symbolic significance when considered as part of the bodily whole.[6] Yet, as noted above, organs and tissues when considered in isolation from the rest of the body seem a source of revulsion and stigma. The relevant question is what religious significance should be attributed in particular to body tissue that may be stored and used for purposes of medical science.

This question is complicated because the approach of medical science to the human body begins from a different starting point, that of "reductionism." The interest of medical science in the body stems from the prospect of gaining information about human character traits and behaviors, including susceptibilities to illness and bodily responses to disease, through study,

analysis and understanding of the basic components of life, such as genes. DNA constitutes the building blocks of life, with cells, tissues, and organs viewed as more complex, functional entities of the basic genetic materials. The scientific value of the body as a totality is instrumental to the goal of deciphering the codes, messages, and functions of the fundamental components of parts of the body that contain valuable information. In this respect, the whole is reduced to the sum of its parts in two respects: (1) genes are more scientifically significant than the body totality; and (2) the value of an organ, tissue, or cell resides primarily in the information it provides researchers, rather than, for example, its significance as a symbol of life.

An illustrative example of scientific reductionism is presented in scientific discourse about the human genome project. Rosner and Johnson have identified three basic metaphors of science discourse about the genome project, interpretation of a "book" or "library," repairing a flawed "machine," or the mapping of a mysterious "wilderness," each of which places the scientist in a dominant and exploitative role. [7] These understandings of a scientific research project involving body organisms contrast significantly with the religious metaphors of the body as "temple" or "sacrament." Thus, while the diagnostic and therapeutic prospects of the genome project are generally viewed with great promise by religious communities, issues may emerge over the reductionist account of the body embedded in genomic research. If, for example, to develop the wilderness metaphor along the linguistic lines common in any issue of the journals *Science* or *Nature*, the human body is understood as merely a "natural resource" for "gene prospectors" to "map," "mine" and make "claims" to establish property rights, patents, and commercial products, then some religious objections may emerge that focus not on the long-term social consequences of the research, but on the intrinsic value of present studies. When the human body of the late 20th century is portrayed in terms analogous to the land of the 19th century, that is, as an exploitable natural resource whose contents are of more interest than the integrity of the whole, then the theological question to modern science is whether the body is only the sum of its constitutive biological materials without remainder.

A prominent model of the body in legal and policy discourse is compatible with the scientific account, but potentially in conflict with theological holism. This is the model of the body as "property." [8] The property understanding stems from a claim of self-ownership, and seeks to authorize the individual person with control over the use and disposition of their body and of body parts. This view tends to treat the body as incidental rather than intrinsic to personal identity; the

body as a totality is distinct from the self, and body organs and tissues can be transferred or alienated to others without compromising the nature of the self. These features make the property model very conducive to the scientific interest in body tissue, with the proviso that informed consent is obtained from the person. However, conflict can arise when, for example, a patient and a researcher assert competing claims or "property rights" to excised body tissues. [9]

These three models ask somewhat different questions about the possibility of using stored tissue samples for research purposes. The question for the scientific and property understandings of the body is what kinds of limits may be placed on research on tissue and transfers of bodily property. That is, the scientific and property perspectives assume the legitimacy of the use of body tissue, and direct attention to the avoidance of abuse. By contrast, the theological emphasis on the embodied self and bodily integrity entail the need to articulate an argument that justifies use of the body. The most common justifying argument in religious thought is that the presumption in favor of bodily integrity and wholeness may be overridden for the purposes of facilitating therapy, the "donation paradigm."

The Donation Paradigm

With very few exceptions religious thought on the body and its use within medicine has presupposed a context within which organs and tissues are donated for therapeutic purposes of healing, restoring or saving life. This moral presumption in western religious discourse is emphasized through the language of "gift," "altruism," or "sacrifice," on the part of the donor and that of "benefits" for recipients. The donation paradigm seems constructed by four principal features:

1) ***Altruistic intent.*** The intent of the donor of an organ or tissue is structured by gift-giving to specific beneficiaries or recipients, such as persons on a waiting list for a transplant (although the identity of such persons may be veiled from the donor).

2) ***Therapeutic expectation*****.** The expectation for the gift of the body is that it will offer a pronounced therapeutic prospect for the recipient. The provision of a needed organ or tissue should offer substantial benefits to the individual beneficiary, whether as enhanced quality of life, or the preserving of life itself. A clear articulation of this therapeutic expectation is found in

Jewish thought, where a general presumption in favor of bodily integrity can be overridden by the paramount imperative of *pikkuah nefesh*, the saving of human life.

3) ***Re-incorporation*.** Body tissue that has been retrieved from the donor, or dis-incorporated, should in most circumstances be "re-incorporated" within the body of the recipient. As noted above, tissue that remains dis-incorporated may evoke sentiments of revulsion and practices of stigma and taboo. Some religious practices and rituals require burial of removed body parts, or re-incorporation in the earth. This is particularly the case with body parts that have an identifiable human form: In Jewish thought body parts composed of "flesh, sinew, and bones," such as limbs, should under most circumstances be buried. Roman Catholic tradition distinguishes major from minor parts of the body in a manner similar to Jewish thought. Major parts of the body are those that retain their "human quality" following excision (a limb) and should be buried.[10] Such concerns may reflect the importance of these visible body parts for self-identity.

Re-incorporation of body organs or tissues in a human recipient has a generative power in that it offers the prospect of new or renewed life to the recipient. In general, then, the donation paradigm prioritizes practices in which body tissue remains with a body (even if transferred and transplanted to the body of another person) and thus symbolizes the significance of bodily integrity and theological holism.

4) ***Recipient Responsibilities.*** The gift of the body carries with it certain responsibilities on the part of the recipient, responsibilities that are embedded in everyday practices of sharing and gift-giving. [11] These include a sentiment of gratitude towards the gift-giver, or towards the institutional structure that mediates the gift transfer. Gratitude should also be enacted in the actions and conduct of the recipient by which he or she makes grateful use of the gift. In addition, a gift induces a responsibility of reciprocity. Reciprocity does not necessarily mean the continuation of the gift relationship between the initial giver and recipient; rather, a recipient of donated blood, for example, may at some time in the future become a blood donor for other strangers.

The donation paradigm as delineated above thus provides a religious ground or justification for medical use of human body tissue. It is limited, however, for the most part to medical practices of transplantation or transfusion, that is, those practices that promise some form

of therapeutic outcome from the gift. Two questions emerge at this point: (1) To what extent is the donation paradigm compatible with the scientific or property understandings of the body? and (2) Can the donation paradigm accommodate non-therapeutic uses of body tissue, namely, uses of tissue for research purposes?

The Resource Paradigm

The different understandings of the body in the scientific and property perspectives carry over into perceptions of the status of body tissue. Following the analogy delineated above, body tissue is a "resource" for scientific study and exploitation. The donative intent of the source of the tissue is attenuated because the tissue may be acquired through surgical procedures, in which case the tissue assumes the status of "surplus" that has been discarded or abandoned, or it may be acquired through a transfer of "property" rights over bodily tissue. In either case, the resource paradigm downplays or neglects the meaning of "gifts" of the body.

Body tissue is a resource because it contains information. The purpose of procuring tissues for research is to generate generalizable knowledge, advancing researchers' understanding of human disease, for example, without necessarily promising therapeutic benefits to individuals, at least in the short-term. This marks out two important distinctions between the resource paradigm and the donation paradigm. First, the recipient of body tissue is different, a member of the scientific research community, rather than the human community in general. In addition, research on body tissue may generate important information in the short-term while deferring therapeutic potential to the long-term. This disparity between research that enhances diagnostic capabilities yet defers therapeutic benefits has played an important role in theological assessments of genetics research, including the ethical implications of the genome project.[12]

Moreover, what is of primary importance in the resource paradigm is not the re-incorporation of bodily tissue, but rather the extraction of information from the tissue. This implies that bodily tissue has no distinctive moral status, and that the information that is retrieved should be treated in a manner equivalent to other forms of medical information. Thus, while the tissue may remain dis-incorporated in perpetuity, safeguards such as privacy and confidentiality are placed around the information.

The notion of recipient responsibilities no less seems attenuated in the resource paradigm

for several reasons. The researcher is not bound by responsibilities of gratitude or reciprocity because it is the work of the scientific community that has made possible the retrieval of the tissue in the first place. There would be no gifts of the body to give were it not for the initial labor of researchers and physicians. This reiterates the paradigm's attribution of "surplus" or "property" to human body tissue. The main responsibility of the researcher-recipient appears to be ensuring that informed consent takes place. However, in the nature of the case, the research process may lead to inadvertent and serendipitous discoveries, so it can be very difficult to anticipate possible research uses of tissue, and thereby disclosure of relevant information by the researcher may be very limited.

Although these contrasts between the donation and the resource paradigms may be somewhat overdrawn, such simplifications should not obscure the point that the paradigms are not easily reconcilable. Indeed, if they were completely compatible, there would not likely be much in the way of distinctive ethical issues in research on tissue samples. The ethical issues emerge because of the conflict between fundamental values embedded in the paradigms, e.g., a personalized gift given for the specific purpose of benefitting another, and depersonalized surplus or property retrieved in order to generate information that may not be therapeutic. This conflict in turn is rooted in the differing approaches of holism of the body, which places the moral burden of proof on those who seek to justify uses of the body, and reductionism of the body, which places the moral burden on those who seek to impose limits on uses and prevent abuses of body tissue that will be used in research. The question is whether there is another paradigm that, on one hand, retains the aspects of gift, benefit, and responsibility embedded in the donation paradigm, and on the other, retains the importance of biomedical research and permits pursuing research in the case of human tissue samples, features vital to the resource paradigm.

The Contribution Paradigm

The use of human body tissue for research poses a challenge to the donation paradigm, which is central to religious understandings of the body and of moral life, because it is not structured by personalized gifts of the body for therapeutic purposes. A different paradigm that seeks to bridge the gap between the donation and resource paradigms is the "offering" or "contribution" paradigm. This paradigm aims to retain the morally valuable features of the donation paradigm, while providing a justification for biomedical research undertaken without

therapeutic intent. The paradigm also acknowledges the importance of medical research to generate generalizable knowledge, but works to impose some limits on the scope and extent of research on human tissues.

An analogy may be useful to illustrate the moral context of this paradigm. Following Belk's suggestion that "the house is a symbolic body for the family," [13] in this analogy household goods take the place of human tissue samples. Household goods can be discarded in several ways, but I will here focus on three ways. One method is to donate certain goods, for example, clothing, to a community goodwill program. This presents an example of a gift or an altruistic action designed to benefit others and to enhance a recipient's quality of life. A different set of household materials are those goods that have been used completely and are now discarded through a community service agency, for example, a trash collection service. Household refuse has no personal meaning to the discarder, who is typically quite willing to pay a fee to have the items removed. This does not, of course, pre-empt the possibility that this refuse might have value to someone else who is willing to take the time to sort through the materials. A third form of disposal consists of those household materials whose designed use has been depleted by members of the household, for example, food products that come in plastic or cardboard containers, but may subsequently undergo "recycling" by those organizations that have the knowledge and expertise to convert these materials into something beneficial for the community.

This analogy underscores the claim that not all body organs and tissues have equal status.[14] Some body parts, such as the heart, eyes, or blood, may have such symbolic significance and connection to personal identity that their donation is the moral equivalent of a gift of self. Other body tissues, for example, urine or cut hair, may have such minimal value to the sense of self that they are routinely discarded. Still other organs and tissues, such as a pancreas, liver, spleen, or bone marrow fall in between these examples, not as central to personal identity as the heart or eyes, but not as incidental as urine either. And, as indicated above, the status of human tissues is shaped not only by issues of personal identity, but also of visibility and hiddenness, and location relative to the bodily totality. In this context, it is possible to think of human tissue samples procured for research purposes as falling in this middle category and thus as analogous to domestic recyclables. The features of this analogy form the basis for the offering or contribution paradigm.

Contributor intent. An individual who places their recyclable materials at the curbside is not necessarily making a personalized gift, but rather is contributing to a cause that is larger than oneself and the benefits one might provide in a direct relationship with another person in need. The cause in the domestic case may be "environmental preservation"; in the case of body tissue, it may be designated as "scientific discovery" or "medical progress." The contribution in both cases is one of non-specific generosity, "non-specific" in that the recipient is a "cause," rather than having a person as the intended beneficiary; it is also a generous act in that a person is participating in the advancement of the larger cause when they could just as easily place the recyclable material in the refuse bin without moral blame.

Beneficial expectation. The contribution does not bring benefits to a specific or designated individual, but the expectation of the contributor is that benefits will over time accrue to the larger whole of society, or least those persons with a stake in the justifying cause. In most instances of contributions, the beneficiary will be future patients, persons, or generations.

One's contribution of either domestic or bodily recyclables provides the raw materials from which persons and institutions with the requisite knowledge can apply their technical skills and expertise. Unlike the resource paradigm, however, the willingness to contribute does not imply that the contribution has minimal or no value to the contributor. A plastic milk jug that can be recycled is equally serviceable as a water jug, and newspaper can be a fire starter. Similarly, a person may attribute value to many tissue specimens, including blood, reproductive tissues, skin or hair that have been retrieved or excised from the body. Rather, the difference between the resource and contribution paradigms lies in the fact that in the latter, something of value is contributed to a person or organization through whose work the society realizes an increased benefit than had the contributor retained the material. The contribution paradigm thereby intends a benefit for the common good of all.

Symbolic Re-incorporation. The religious understanding of the body that prevails in the west commonly requires some practices or rituals that re-incorporate those tissues that are removed from the body into another body, whether an organ transplant or blood transfusion into a person, or burial in the earth. The contribution paradigm can meet this condition through symbolic re-incorporation. Just as recycling contributes to the good of the communal body, the contribution of body tissues for research can provide information that can then be integrated within a larger,

symbolic body, namely, the "body of scientific knowledge."

Recipient Responsibilities. Contributions in general are acknowledged in some form by the recipient; it thereby seems important for contributions of bodily tissue to be acknowledged with some expression of gratitude. This might occur through the informed consent ritual, in a researcher should not presume that the contributor should simply "sign off" to any and all uses made of retrieved body tissues, but instead might directly thank the person for their contribution to the advancement of scientific research. The researcher-recipient also has a responsibility to use the contribution of body tissue for the common good. At a minimum, this requires treating the information generated by tissue research with safeguards that ensure protection against discrimination or harm. The appeal to the "common good" also does not necessarily preclude recourse to the private sector to carry out research; in some cases, as with domestic recyclables, the good of all can be more efficiently and effectively achieved through private sector initiatives. However, any profit interests must be subordinated to and limited by the common good and the greater cause that the contribution is designed to advance. In short, retrieved body tissue cannot be viewed as merely an economic asset.

The contribution paradigm thus provides a justification for research uses of human body tissue, a justification that was absent in the donation paradigm due to its focus on direct therapeutic prospects. It also imposes limitations on research, such as the importance of the common good, re-incorporation, and informed consent, that seem absent in the resource paradigm due to its focus on using the body merely as a means to generate generalizable information. The chart below summarizes the overlaps and similarities of the three paradigms:

TABLE 1
PARADIGMS

Characteristics	*Donation*	*Resource*	*Offering/Contribution*
Intention	Gifts of the body	Research on body "surplus"	Participation in "larger" cause
Expectation	Therapy for recipient	Generate information	Benefit to larger whole

Outcome of Body tissue	Re-incorporation in body and "new life"	Safeguard information	Re-incorporation in symbolic body (e.g., scientific knowledge)
Recipient Responsibilities	Gratitude, Reciprocity	Informed consent	Acknowledgment, Informed Consent, Safeguards, Common good

The question then is to examine the extent to which a contribution paradigm is compatible with specific religious attitudes towards the human body and body tissues.

Implications of Embodiment

The analysis to this point has situated ethical issues in research on human tissue within the broad framework of the western religious tradition. The issues and conflicts may be different when consideration is given to the pluralism present in religious thought on the status of the body, the body's relationship to self, and the status of body parts. Protestant theologian William F. May has distinguished five "religious" attitudes on the status of the body and its parts that are useful to review in the context of retrieval of human tissue.[15]

DUALISM------GNOSTICISM-------EMBODIMENT--------MATERIALISM--------IDEALISM

This typology relies on distinctions over whether the body has a phenomenal reality, is ontologically good, and is intrinsic or incidental to personal identity.

Dualism affirms the phenomenal reality of the body but denies its goodness because of the body's association with flesh and matter. Dualism portrays the body as "at war" with the self, its literal mortal enemy. Parts of the body, disposal of the body, and persons who come into contact with the corpse are denigrated, stigmatized and considered taboo and sources of pollution or uncleanness.

At the opposite end of the continuum, idealism denies that bodily life has any ultimate

significance. The body, disease, and death are constructs of the mind that can be transcended through identification with a separate realm of the spiritual. The self seeks its true home in this spiritual realm, and relies on spiritual healing rather than on medical ministrations to achieve this goal. Body parts, or study of the body, are not denigrated as much as seen as existentially indifferent.

The gnostic attitude seeks liberation of the true self from the body, which is understood as a prison of the soul. The true self resides in a disembodied mind or consciousness. Knowledge is the means to liberation, which entails overcoming the burdens of mortality, including finitude, disease and death. Body parts have no significant value.

Hindu and Buddhist teachings about life's purpose reflect a similar appraisal of the secondary status of the body and the necessity of liberation from the bodily world. The body is incidental to personal identity—indeed, a self may be incarnated in several bodies—and the true self resides in a realm of trans-bodily consciousness.

In the West, May argues that the gnostic attitude lives on in the form of philosophical Cartesianism. The Cartesian separation of self(mind) and body(matter) is embedded within the ideology of biomedical research; as exemplified above, the body is perceived merely as a "resource" for obtaining raw biological materials that can, through study and application, be converted into drugs that offer mastery over nature.[16] The Cartesian separation of self and body has a further consequence, namely, that there is no moral necessity for informed consent to the removal of bodily tissue, or subsequent research and manipulation. Since a body is incidental to personal identity, the retrieval of an organ, tissue, or cell cannot be said to violate the person and their integrity, even if their bodily space is violated. In this respect, informed consent appears to be a rule without a rationale. Its use under the resource paradigm may be a signal of the general inadequacy of that paradigm with respect to human tissue research.

In contrast to an approach that seeks to master nature, the materialistic attitude to the body is shaped by an ideology that human life is at the mercy of powers in nature that are arbitrary, abusive, and destructive. This can lead to two different, and conflicting, perspectives both of which are present in western cultures, avoidance and denial (e.g., of aging or death), or resistance. The latter belief is enacted primarily through the practice of medicine and its war on

death and human disease. In this perspective, the body assumes the role of primary "battleground." Patients may well give consent to invasive procedures, but the patient is principally a passive observer to the battle plan carried out by physicians and researchers. A successful waging of the war often requires excision of body parts or removal of tissue; such parts thereby possess instrumental value but no intrinsic value.

Within this typology, the dualistic, gnostic, and materialistic perspectives can be construed as compatible with the resource paradigm of biomedical research. The idealistic attitude, by contrast, finds in medical research a misguided attempt at medicalization of the metaphysical. This implies that scientific proposals for research on human tissue samples become an ethical issue only in those traditions that understand embodiment—that is, the intrinsic relationship of body and self—as a fundamental given of human life. Such attitudes are embedded in the monotheistic religious traditions of Judaism, Christianity, and Islam. These traditions affirm the ontological reality of the body as well as its intrinsic moral goodness, in contrast to the instrumental value embedded in Cartesian and materialist thought. Moreover, the western traditions affirm the intrinsic nature of the body to personal identity: Human beings are embodied selves, not simply a soul or a mind housed within a corporeal prison.

These features provide a religious and moral validation for medical interventions in the body. The reality and goodness of the body entail the use of medical procedures to restore and heal. The fundamental connection of body and self makes consent of the person a moral mandate with respect to invasive medical procedures and removal of bodily tissue, healthy or diseased. However, the rationale for consent does not necessarily presume personal ownership of the body. Instead, control over the body and its disposition is rather a responsibility often portrayed as "trusteeship" or "stewardship" from the Creator.[17] Responsible stewardship involves accountability for uses of the body and an orientation of such uses toward the common good. Ethical positions and liturgical rituals, for example, can justify sharing of the body as a form of altruistic service to others. The trusteeship understanding thereby rules out viewing the body merely as property or merely as a resource for economic gain.

Within these traditions, it is clear that the donation paradigm is prominent with respect to organ transplants or transfusions of vital tissues. Discussion of use of body tissues retrieved for research or educational purposes is minimal. It is possible to begin, however, by considering

theological perspectives on issues raised by donation of the whole body to medical schools for research or teaching purposes and by requests for autopsies. These provide some examples of uses of the body in medicine without direct therapeutic benefit, and thus may illuminate important theological principles and precedents.

BODY DONATION AND DISSECTION

Within Judaism, some debate exists about the moral status of donating the whole body to medical schools for the purpose of educating prospective physicians. This dispute reflects differences over the priorities given to two primary obligations in Jewish law. There is a presumptive obligation, *kavod ha'met*, that supports preserving the integrity of the corpse as a symbol of the person and as a requirement of care for God's creation; this precludes desecration of the corpse. However, this presumption can be overridden (as can all commandments in Jewish law, save for prohibitions against murder, idolatry, and illicit sexual relations) by the requirement of *pikkuah nefesh*, the saving of human life.

Within the moral framework set by these two principles, some Orthodox rabbis object to body donation unless it has an immediate practical benefit to a needy patient. Other rabbis permit body donation in principle because it contributes to medical education and future patients can benefit through the anatomical studies carried out by present researchers. The principal proviso in this understanding is that the body parts dissected for study be preserved and eventually receive a respectful burial in conformity with Jewish law.[18] The emphasis on burial and re-incorporation of the body in Judaism is also illustrated by the practices of ultra-Orthodox Jews in Israel, who, following a terrorist bombing seek to locate dismembered body parts so that they will receive a proper burial.

While Jewish thought appears to permit donation of the body to medical science in principle, Jewish scholars have cited a surplus of cadavers available for research and training at medical institutions to contend there is no practical imperative within the tradition.

The Islamic understanding of the human body also stresses the importance of body wholeness at death. Islam affirms a general presumption against donation of the body for anatomical dissection that reflects the principles of the dignity of the human body and a

prohibition on mutilation of the body. Anatomical research in Islamic medical schools is instead frequently performed on animals.[19]

AUTOPSY

The Jewish approach to autopsy again invokes the two basic principles of non-desecration and the preservation of life. Within this moral structure, autopsies may be permitted under certain limited conditions: when legally required; when the cause of death cannot be determined; when an autopsy may help save the lives of persons suffering from an illness similar to the cause of death of the deceased; or when relatives might be protected by learning of hereditary illness.[20] In the rare circumstances in which an autopsy is performed, only small blood, fluid, and tissue specimens can be removed for analysis; organs must be examined intact within the body, and the body must be buried whole.[21]

In the Roman Catholic tradition, Pius XII declared that autopsy can be morally permitted so long as two conditions are satisfied: (1) the body must be treated with respect and not objectified or treated as a "thing," and (2) the family of the deceased person gives consent to the procedure.[22]

The strong presumption in Islamic thought on bodily wholeness at the time of death limits the scope of acceptable autopsies. Autopsy is therefore not a routine medical procedure, but the presumption can be overridden and accommodate request for autopsies in cases where death occurs from suspicious causes.[23] This precludes use of human tissue for research purposes.

Other religious traditions that have articulated objections to autopsies include Orthodox Christianity, Hinduism, and Shinto (the indigenous religion of Japan). It is also common for Native Americans to refuse to give permission for autopsy, unless it is an absolute legal requirement.[24] Protestant perspectives on autopsy, by contrast, generally reflect deference to familial autonomy. Autopsy is a permissible procedure if the family of the deceased consents.

FETAL TISSUE

Another context for religious discussions of research on bodily tissue is that of fetal tissue

research, although this is not as clear an illustration because procurement of fetal tissue is complicated by its moral proximity to abortion. In discussion before the NIH Human Fetal Tissue Transplantation Research Panel, rabbinic arguments invoked the principle of *pikkuah nefesh*, that is, therapy to a specified individual, as a condition of justification. Research on fetal tissue, by contrast, was portrayed as "research protocols with undetermined and remote benefits for future patients, rather than therapeutic protocols with high probabilities of immediate benefits for current patients." [25]

Roman Catholic teaching holds that a fetal cadaver should receive the same respect as the corpse of any human being and that obtaining fetal tissue for research purposes from direct abortion constitutes complicity in moral evil. Other religious objections have focused on the possible commercial exploitation of fetal tissue. [26]

CONCLUSIONS

These few examples of religious discussion regarding use of the human body and human tissue for purposes of research and education reiterate the importance that religious traditions attach to the integrity and totality of the body. Even under the circumstances in which body donation or autopsy is deemed permissible (or legally required), researchers and teachers have an obligation to maintain respect for the corpse as a symbol of the person. Beyond these rather limited examples, there seems to be minimal religious discussion of use of human tissue for research purposes that are acquired from living persons through routine medical procedures, e.g., a blood draw, post-partum retrieval of a placenta or umbilical cord blood, or surgical excisions. A recent study on ethical issues in the banking of umbilical cord blood, for example, recommended sensitivity to "the variety of beliefs held regarding the placenta and umbilical cord" of individual patients, but acknowledged a general "dearth of information" with respect to more general cultural attitudes.[27] Yet, in many indigenous cultures, include Native American, the placenta, umbilical cord, and umbilical cord blood have sacred symbolic value associated with the creation of life and personal identity.[28] This disparity between the meaning of body tissue to researchers and its meaning to members of religious cultural traditions should be a central concern of public policy.

Public education on human tissue banking is vital.

It is difficult to interpret the meaning of silence of religious traditions on medical issues. In some cases, ecclesiastical silence may reflect a particular tradition's commitment to personal autonomy and conscience in making health care decisions. In other traditions, silence may indicate the question at stake is morally indifferent, in which case a decision is deferred to the individual. Given the strong convictions about the body present in most religious traditions, however, the absence of religious discussion on tissue banking for research purposes may also reflect widespread lack of awareness. It seems education of the public, including citizens who are members of religious communities, is an essential part of concerted public policy on use of human tissue for research. NBAC would be well-served by reiterating its concluding recommendations from Cloning Human Beings concerning "widespread and continuing deliberation" and the provision of "information and education to the public in the areas of genetics, and on other developments in the biomedical sciences, especially where these affect important cultural practices, values, and beliefs." [29] This prior recommendation encompasses the kinds of issues raised by tissue banking and the implications of such research on important value systems, including religious values. Moreover, as it is the research community that seeks access to human tissue, for policy purposes a moral burden should fall on researchers to elicit from prospective tissue contributors, both individual and communal, the values and meaning they attach to the requested tissue.

One important rationale for public forums that provide a clear account of ongoing or proposed research is that they can pre-empt religious objections to research on human tissues that are based on fuzzy understandings of science and muddled theology. The most prominent recent example of conflict over the status of human tissues and genes occurred in May 1995, when a coalition of some 200 religious leaders encompassing over 80 different religious bodies made a public call for a moratorium on the patenting of any human and animal life forms.[30] While theological arguments were offered for the moratorium, some of which seemed misdirected, behind the call for a moratorium is a valid concern over the public accountability of biomedical and genetics research (and its commercial development), including the need to consider the implications of research for important religious values.

The informed consent process for obtaining authorization to use human tissue for research should be specific, substantive, and sensitive to religious values about the body, both personal and communal.

"Religious" beliefs, such as belief in an afterlife or in bodily resurrection, have been commonly cited as grounds for refusal to sign organ donor cards; in the absence of general public awareness, it is likely that similar objections may surface when requests are made to use retrieved tissue for research purposes. In its deliberations, NBAC identified several different reasons for patient dissent to research on tissue samples. These included (a) general distrust of science (underscoring the importance of the initial recommendation for public education and accountability); (b) the alteration of scientific purposes from the rationale when informed consent was first obtained; c) concerns about personal, familial, or communal identity; (d) the potential for research results to be used in such a way as to risk social stigma and discrimination; and (e) religious reasons (which could encompass concerns about both identity and stigmas). The religious status of informed consent thereby seems an important consideration in formulating practical public policy.

Informed consent was described by the Protestant ethicist Paul Ramsey as the "cardinal canon of loyalty" between patient and professional in medicine, whether physician or researcher.[31] Informed consent was the tangible expression of an implicit covenantal bond between the patient (as person) and professional in a *joint* enterprise of developing medically-useful knowledge. This influential understanding of the meaning of informed consent requires a version of "thick" or specific consent to use of human tissue samples, rather than a general or implicit consent to any research and educational uses a research protocol might develop for analysis of tissue. Specific consent is compatible with and extends the values underlying the contribution paradigm and makes it possible for persons to understand themselves as contributing partners in the scientific enterprise of generating important knowledge.

Moreover, in some religious traditions, the informed consent process may be viewed as reflecting respectful or cavalier attitudes to the body. Roman Catholic teaching emphasizes that informed consent should protect the dignity of the human person, but it can only do this when physicians or researchers adopt a holistic rather than reductionistic view of the patient as person. John Paul II stated that "in the body and through the body, one touches the person himself in his concrete reality." Thus, even though physicians and researchers may have a scientific interest in specific body tissues, the informed consent process should inform and respect the embodied self rather than proceed as though the self is a disembodied will.[32]

In the process of information disclosure and descriptions of benefits and risks, professionals should be cognizant of the significance of "symbolic" harms for members of religious communities. The language of biomedical description can hinder understanding and comprehension within some communities, as revealed in studies on information disclosure among the Navajo culture.[33] Researchers thus need to be familiar with, and sensitive to, the communicative processes within a religious or cultural tradition.[34]

The idea of symbolic harm is often placed at the boundaries of bioethical controversies, portrayed as a mere "sentimental" or "speculative" concern rather than as a tangible substantive harm equivalent to the direct injury of the person. Yet, religious traditions are very centrally organized around symbol-systems; indeed, "symbolism is the language of religion generally; it is to religion what numbers are to science."[35] Issues of symbolic harm should be not be dismissed in the research setting. As described above, the body is a symbol of the divine in much religious thought. Symbolic harms inform religious restrictions on, for example, appropriate treatment of the corpse, such as the prohibition of desecration found in Judaism, thus placing off-limits body tissue that might otherwise provide important medical knowledge through dissection or autopsy. The study and subsequent disposal of body parts, rather than conforming to the contributor expectation of burial, also constitutes harm of a symbolic nature.

The patient should be regarded as possessing dispositional authority over his or her body, and over the specific research uses of retrieved human tissue for which informed consent is sought.

The concept of ownership is comprised of a "bundle of rights," including rights to use, transfer (via donation or sale) or dispose of a thing one owns.[36] It has been argued that, since religious traditions generally recognize the liberty of person to donate organs or tissues, this constitutes an implicit property right of the person to their body parts. This interpretation seems to contravene the basic theological conviction of the western traditions that any "ownership" rights to the human body reside in the Creator, and that persons are trustees or stewards over their bodies, not owners.

There are two different approaches to resolve this potential conflict. A first approach might accept the validity of the ownership-property model, but still seek to distinguish between

God's creation (the body) and human intervention (retrieval of body parts). A second approach claims that concepts of ownership and property are misguided ways to think about the human body and its parts. Property discourse, which is shaped in large part by market values, effectively preempts other discourses of value about the human body, including religious discourse. [37] Property discourse emphasizes a relationship with "things"; the theologies of the body outlined in this report consider the body so intrinsic to personal identity and invest the body with such symbolic significance, as conveyed in rich imagery as "temple" or "sanctuary," that attribution of status of "thing" to the body is simply inadequate.

This function of property discourse about the body is no different than the historical role of property discourse: "Property" is the language of power. Property discourse empowers an agent with decision-making authority about use, transfer, and disposal, whether it be land or ideas ("intellectual property"). It seems possible, and from a religious understanding, desirable, to refer to the person whose body tissues might be donated or retrieved as holding dispositional authority over the body without presuming that this authority implies ownership or property rights. Since trustees and stewards can be authorized to share the goods entrusted to them for the benefit of others, this distinction between dispositional authority and property rights does not impugn the ultimate sovereignty or ownership of the Creator over the body.

Contributions of human body tissue for purposes of advancing scientific research and knowledge are ethically preferable to other modes of acquisition of tissue, such as sales or abandonment. Any compensation to individuals for their contribution should not presuppose or encourage an organized and regulated market in human tissue.

The donation paradigm and contribution paradigm are strongly supported in western religious discourse by discourse and symbols of "gifts," "sacrifice," and "altruism." This emphasis presents important questions regarding the prospects of acquiring bodily tissue sales. The latter approach seems more compatible with the resource and property understandings of the body. The Protestant ethicist William May is especially critical of proposals for commerce in the body, arguing that they reflect "no religious view but rather ... a wholly secularized marketplace that permits one to reduce any and all things to assets for sale."[38] The claim that the religious status of the body is incompatible with a market in body tissues and cells resonates even with non-religious writers, who nonetheless appeal to religious language of "reverence," "sacred" and "image of

God" to express criticism of property and market models of the body and of human biological materials.[39] It seems fair to state that religious thought, in addition to objecting to scientific reductionism of the body, also would find economic reductionism morally problematic.

Roman Catholic teaching has expressed some openness to compensation of donors, though not to a full-scale organ or tissue market. Pius XII expressed concern about the "grave abuses" that may ensue from routine market transactions in bodily parts, but qualified his reservations by stating, "it would be going too far to declare immoral every acceptance or every demand or payment. It is commendable for the donor to refuse recompense: it is not necessarily a fault to accept it."[40] The donation and contribution paradigms are perhaps best embodied and facilitated by altruism, but compensation--which is morally and institutionally different than a system of commerce in body parts--may be ethically acceptable for some religious traditions, although not ethically ideal or preferable.

In the case of abandoned tissue, it has been argued that the central issue turns on the understanding component of informed consent: "The fundamental question is whether the original possessor of the biological materials in question understood when he or she relinquished control over those materials that they would be used in research rather than destroyed." Indeed, "it is ethically unacceptable for researchers simply to take putatively abandoned or unclaimed tissues and use them in research projects without informing patients about that use."[41] This assessment seems compatible with the religious claims advanced above, in which it is insufficient for researchers interested in studying bodily tissue to rely on a general consent, or tacit or implicit consent. The patient should express explicit consent and should clearly understand the implications and meaning of this consent. A consent to contribution of body tissue does not constitute a transfer of property, but rather involves the transfer of dispositional authority.

Procedures for retrieving, storage and research use of human tissue should incorporate provisions of protection of confidentiality. Such procedures should also provide protections for communities.

The preceding analysis has emphasized the importance in religious thought of the body as partly constitutive of personal identity. While the retrieval of tissue from the dis-incorporated body may diminish the intrinsic connection of self and body in many circumstances, the prospects

of genetic analysis of tissue samples and research constructions of a person's genotype can reaffirm this connection in important and potentially risky ways. The concern here is not an expression of theological reductionism, that is, a view that personal identity is derived from genetic make-up. Rather, the issue is that, in a society in which genetic information may be highly valued to parties outside the contributor-researcher relationship, disclosure of this information to such parties may have a significant impact on a person's social self. The religious understandings of the body therefore establish a strong presumption in favor of the protection of this information as confidential.

The justification for confidentiality is embedded in the features of the contribution paradigm. The moral intent of the contribution is to facilitate the advance of biomedical research through the generating of generalizable knowledge. Research that discovers and discloses specific, identifying information, by contrast, risks violating the moral intent of the contribution. Moreover, a contribution entails recipient responsibilities, including a responsibility to prevent harm or discrimination from befalling tissue contributors. These features present presumptive arguments in favor of protection information as confidential. Moreover, it is possible in some research studies that study samples taken from members of a larger community, for the community to experience harms and stigmas due to information disclosure, even if the particular individuals from whom tissues are retrieved are anonymous. These protections do not preclude contributors from waiving claims of confidentiality.

Within these justifications and limitations, it seems possible to both respect and acknowledge the sacral role of the body in religious discourse and practice, and promote promising directions in research on human tissue. It is difficult to situate the ethical dilemmas posed by biomedical research on human tissue within a context of various religious understandings of embodiment, and the centrality of the body to personal identity. However, if there is one common theme among this theological diversity it is the affirmation of the moral significance of the body in its organic totality and a concern that biomedical research may encourage a reductionist attitude towards the body. In so doing, the awe demanded by the presence of an embodied person will be diminished as the self is seen primarily as a disembodied will. The central theological concern is that the sacral role of the body be acknowledged in order to justify biomedical research on bodily tissue.

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