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ETHICS OF CRYOPRESERVED EMBRYO ADOPTION: DEFROSTING DIGNITAS PERSONAE
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Ethics of Cryopreserved Embryo Adoption: Defrosting Dignitas Personae

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It has also been proposed, solely in order to allow human beings to be born who are otherwise condemned to destruction, that there could be a form of “prenatal adoption.” This proposal, praiseworthy with regard to the intention of respecting and defending human life, presents however various problems … — Dignitas Personae (2008), II. para. 19.

As of 2015, estimates suggest that there are over 600,000 cryopreserved embryos stored in the United States, of which around 60,000 are available for adoption.¹ The embryos exist because current protocols for in vitro fertilization (IVF) and embryo transfer (ET) for infertile couples seek to maximize the chance of successful implantation while minimizing the risks of therapy. The method used to achieve this end is the simultaneous creation of up to two dozen embryos, of which some are implanted into an awaiting woman and some are stored in the event that the first implantation is unsuccessful. As more couples seek IVF as a solution to their infertility, the number of cryopreserved embryos in storage continues to grow.

The church has spoken clearly on the morality of the process of creating these embryos in the first place. *Dignitas Personae* states unequivocally that, “Cryopreservation is incompatible with the respect owed to human embryos” (*Dignitas Personae* [2008], II, para. 18; emphasis original). The parent document to *Dignitas Personae*, *Donum Vitae*, succinctly provides the reason for this imperative: “The human being must be respected – as a person – from the very first instant of his existence” (*Donum Vitae* [1987], I, 1).² *Dignitas Personae* goes on to state, “The proposal that these embryos could be put at the disposal of infertile couples as a treatment for infertility is not ethically acceptable …” (*DP*, II, para. 19).

However, despite the seeming clarity of the statements in *Dignitas Personae*, there remains debate not only over embryo adoption, but also over the meaning and specificity of the statements in the magisterial document. John Finnis and Luke Gormally debated this point in a 2009 edition of The National Catholic Bioethics Quarterly, with Finnis arguing that the document does not make a definitive pronouncement, and Gormally offering an opposing position.³ Following this, the NFP Forum, a biannual publication of the United States Conference of Catholic Bishops, kept open the door for continued debate by declaring that *Dignitas Personae* does not “make a definitive judgement” regarding embryo adoption.⁴

In this essay, I examine the logic contained in *Dignitas Personae* to the support of its position, and ultimately conclude that embryo adoption of previously created and cryopreserved embryos is morally licit, and in fact is a charitable response to an existing injustice.

**INITIAL CONSIDERATIONS**

As an entry point to the discussion of human embryo adoption, it is necessary to define the terms and outline certain theological propositions and assertions that I will accept as true for the duration of the argument.

The ontology of human life has been discussed at length by numerous authors. Medical science provides a view of human reproduction that understands the sequence of events from intercourse to pregnancy to birth in fine, but not perfect, detail. Beginning with the ovum of a female and the sperm of a male (the gametes), fertilization occurs upon the fusion of the nuclei of these two individual cells. At this point, from the partial genetic contributions of two individuals, a third individual has begun a journey during which it will self-develop into a human person.⁵ Some writers have made semantic arguments about the difference between a human being and a human person, arguing that although a fertilized embryo unequivocally contains the genetic material necessary to make it (genetically) a human, it is not yet a human person because it lacks consciousness. For this reason, some authors refer to the fertilized embryo that has not yet implanted itself into the uterine wall as a pre-embryo. From the point of implantation, the embryo develops into a zygote, morula and blastocyst sequentially, and then continues to divide and develop.

The Catholic Church, in teachings regarding the ontology of human life, is clear that
regardless of the stage of development, each of these stages should be afforded identical ethical relevance, and that from the moment of fertilization, a new human being is already constituted and must be respected as such. There remains, of course, a contemporary disagreement about this point, as the church insists on respect for human persons because of their ensoulment, and, “[no] experimental datum can be in itself sufficient to bring us to the recognition of a spiritual soul” (DV, I, 1). However, while recognizing the difficulty with the determination of the time of ensoulment, the teaching continues,

[...]evertheless, the conclusions of science regarding the human embryo provide a valuable indication for discerning by the use of reason a personal presence at the moment of first appearance of human life: how could a human individual not be a human person?... Thus the fruit of human generation from the first moment of its existence, that is, from the first moment the zygote has formed, demands unconditional respect, that is morally due to the human being in his bodily and spiritual totality (DV, I, 1).

While some authors have taken the church document as acknowledging a degree of doubt regarding the personhood status of the embryo, it remains true that the church has spoken clearly about the respect due to the embryo, which has been a rallying cry of the pro-life movement. Concomitant with the abortion debate, technology has also been advancing ways in which to artificially assist the production of embryos as an aid to infertile couples.

Artificial reproductive technologies (ART) have been hailed as a treatment for infertility, and they have rapidly gained popularity despite their high monetary cost. However, as noted above, by the nature of these technologies, they produce fertilized embryos in excess of what is strictly necessary for a single round of therapy. This has led to the banking of embryos, which are placed in a chemical preservative and frozen for future use. Around 90% of these are technically considered to be “in use” by the couples from whom they were created, which accounts for the numerical disparity between the existing cryopreserved embryos (about 600,000) and those available for embryo adoption (around 60,000). Embryo adoption agencies acquire available embryos on behalf of couples who seek to adopt the embryo as their own child through embryo transfer to the (unrelated) mother’s uterus. This is accomplished via a catheter which is inserted into the uterus and used to transfer heterologous, fertilized embryos for hopeful implantation. Some agencies, in keeping with a preferential option for the poor, use the lowest quality available embryos to ensure that even the most vulnerable are given a chance to be gestated and born.

The process of embryo adoption has been compared to surrogate motherhood, so it is of key importance at this point to define surrogate motherhood, which is an important concept in the analysis of several authors. Surrogate motherhood occurs when a woman carries a pregnancy for another woman or couple with the agreement that the baby will be returned to the biological parents after being born. The
surrogate pregnancy may be produced through natural or artificial means, and the arrangement may result in monetary compensation for the surrogate. This concept will be discussed further as I consider the relevant church documents and arguments of prominent theologians.

Prior to engaging the ongoing ethical and theological debate, it is first important to understand the content of Donum Vitae and Dignitas Personae. I will examine the content of the church documents as a foundation to further discussion, and following a discussion of the current debate in the literature, I will offer some comments on the structure and logic of the church documents.

**DONUM VITAE**

*Donum Vitae* was written in 1987 by then Joseph Cardinal Ratzinger, who was at the time the prefect for the Congregation for the Doctrine of the Faith. The document was approved and ordered for publication by Pope John Paul II. In many ways, it is the parent document to *Dignitas Personae*, offering strong influence to the later document and supplying much of the logic and language. For that reason, although it does not address embryo adoption directly, it is an important document to consider in the discussion on embryo adoption. The document seeks to answer specific questions that had been raised at the time by members of the church concerned about the implications of new reproductive technologies. It is a document in three parts, which opens with an anthropological and moral examination of fundamental principles, then moves to moral questions raised by the emergence of new reproductive technologies, and finally attempts to provide guidance on the relationship between moral and civil law regarding human embryos. Following are some key aspects of the document that bear relevance to the discussion at hand:

The gift of life which God the Creator and Father has entrusted to man calls him to appreciate the inestimable value of what he has been given and to take responsibility for it: this fundamental principle must be placed at the centre of one’s reflection in order to clarify and solve the moral problems raised by artificial interventions on life as it originates and on the process of procreation (*DV*, Intro., 1).

The document then begins to provide answers to specific questions, and I will address some
of the key questions here. First, Ratzinger asks what respect is due to the human embryo, and in a refrain to be repeated often, writes that the human being must be respected from the moment of conception. He speaks against procured abortion, and refers to this teaching as unchangeable. He then, in comments that will presage the embryo adoption debate, writes that the embryo, as a person, must be “defended in its integrity, tended and cared for, to the extent possible, in the same way as any other human being as far as medical assistance is concerned” (DV, I, 1).

He further poses the question of whether therapeutic procedures may be licitly carried out on the human embryo. Again, we have a key question for the future embryo adoption debate, as implantation of a formed embryo might be considered a therapeutic procedure. Outside of procedures carrying disproportionate risk, the conclusion is that procedures should be allowed so long as they respect the life of the embryo and are directed toward its “healing, the improvement of its condition of health, or its individual survival” (DV, I, 3).9

The document then proceeds to address the questions of procreation and surrogacy, both of which become key considerations around embryo adoption. Ratzinger writes that the “child has a right to be conceived, carried in the womb, brought into the world and brought up within marriage” (DV, A, 1), and he then concludes that IVF is contrary to the unity of marriage because it separates the procreative act from the marital act, and as such violates not only the dignity of marriage but also the rights of the child. Utilizing similar logic, the Instruction concludes that surrogacy must be rejected as morally illicit because it is contrary to the unity of marriage and dignity of procreation. Donum Vitae defines the surrogate mother as the woman who carries in pregnancy an embryo implanted in her uterus and who is genetically a stranger to the embryo because it has been obtained through the union of the gametes of “donors”. She carries the pregnancy with a pledge to surrender the baby once it is born to the party who commissioned or made the agreement for the pregnancy (DV, A, 3).10

While none of these considerations touch directly on embryo adoption, the focus on the beginning of life and the application of emerging technologies to the generation of life has made this document an important consideration for some people concerned with the moral status of embryo adoption. Not least among writings that consider the document influential is Dignitas Personae, which brings us face to face with a discussion of embryo adoption.

DIGNITAS PERSONAE

Dignitas Personae was written in 2008 by William Cardinal Levada, who was at the time the prefect for the Congregation for the Doctrine of the Faith. The document was approved and ordered for publication by Pope Benedict XVI, who 20 years earlier had penned Donum Vitae. Dignitas Personae acknowledges in its introductory remarks that it is an extension and updating of Donum Vitae, which it holds as completely valid, but merely in need of updating in the face of new reproductive technologies. Similar to the older
The new Instruction is organized in three parts, with an opening consideration of anthropological and theological concepts, followed by two sections addressing new problems with procreation and embryo manipulation, respectively.

Dignitas Personae notes that, despite frequent exhortations to respect the embryo as possessing personhood, Donum Vitae avoided making the philosophical conclusion that an embryo is a person. However, the document goes on to say that embryos possess “full anthropological and ethical status” and have “from the very beginning, the dignity proper to a person” (DP, I, para. 5). The teaching then examines the context in which human life should be brought into existence (in marriage), and examines the human and divine dimensions of procreation. The introductory section closes with a reminder that “unconditional respect [is] owed to every human being at every moment of his or her existence” (DP, I, para. 10).

The second part of the document contains the passages most central to the embryo adoption debate. In addition to reiterating the teachings of Donum Vitae regarding IVF, the new document emphasizes three “fundamental goods” that new medical techniques for the treatment of infertility must respect:

a) the right to life and to physical integrity of every human being from conception until natural death; b) the unity of marriage, which means reciprocal respect for the right within marriage to become a father or mother only together with the other spouse; c) the specifically human values of sexuality which require that the procreation of a human person be brought about as the fruit of the conjugal act specific to the love between spouses (DP, II, para. 12).

Following an examination of IVF, the document notes that frozen embryos are often created during the process of IVF, and deplores cryopreservation as “incompatible with the respect owed to human embryos”, and even referring to the unused embryos as “orphans” (DP, II, para. 18). Following this, the document presents a section dealing specifically with embryo adoption. The section opens by posing the question of how we should address the fact that large numbers of frozen embryos already exist in storage. Rejected outright is the idea that frozen embryos might be used for research purposes or the development of disease treatments. This solution would treat the embryos as an object to be manipulated and used toward some other end, and is therefore unacceptable.

The document then makes a quite subtle differentiation between couples who would utilize the embryos in a heterologous transfer as a treatment for infertility and those who would “prenatally adopt” the embryos with the charitable intent of sparing them from destruction. Regarding the former, Levada writes, “The proposal that these embryos be put at the disposal of infertile couples as a treatment for infertility is not ethically acceptable for the same reasons which make artificial heterologous procreation illicit as well as any form of surrogate motherhood” (DP, II, para. 19). Regarding the latter situation, he continues,

It has also been proposed, solely in order to allow human beings to be born who are
otherwise condemned to destruction, that there could be a form of “prenatal adoption.” This proposal, praiseworthy with regard to the intention\(^1\) of respecting and defending human life, presents however various problems not dissimilar to those mentioned above (DP, II, para. 19).

The section closes with John Paul II’s appeal to halt production of frozen embryos and afford those in existence protections under the law. Levada also notes that the existence of hundreds of thousands of frozen embryos represents a “situation of injustice which in fact cannot be resolved” (DP, II, para. 19).

### ENGAGING THE DEBATE

In his analysis of the aforementioned documents, Luke Gormally puts forth several arguments against embryo adoption. He opens by highlighting the word *intention* in n. 19 of *Dignitas Personae*, which he notes can refer only to the intended end of the practice and not to any means used in the service of that end.\(^1\) In other words, though the desired end of rescuing a frozen embryo is laudable, the means available to achieve the end encompass, as the document tells us, “various problems.” Because *Dignitas Personae* notes the problematic nature of the means at our disposal to reach the “intention,” Gormally interprets the church document as making a negative pronouncement on the practice of embryo adoption, though he admits this teaching is not strongly worded.

Gormally rightly notes that the church document is clear in its teaching that the natural and authentic origin of the child is from the marital act, and a husband and wife have an inviolable right to make each other, and only each other, into father and mother. However, he continues that in embryo adoption, the woman does not become a mother through her choice to engage in intercourse with her husband, but rather through a choice to have a previously created embryo implanted in her uterus. Here Gormally refers back to the fine distinction noted above between the use of frozen embryos as a treatment for infertility and the idea of their prenatal adoption; he applies the rationale for rejecting embryo use as fertility treatment, that is “the same reasons which make artificial heterologous procreation illicit” to the process of embryo adoption (DP, II, para. 19). Heterologous procreation is illicit because it “causes a complete separation between procreation and the conjugal act” (DP, II, para. 17). If that separation then makes illicit the use of frozen embryos as a treatment for infertility, Gormally concludes that the same must be true for embryo adoption.

In addition, though it is not the express intent of *Dignitas Personae* to address this niche issue, Gormally comments on the idea that a woman might adopt an embryo in order to save its life and then give the baby up for adoption. In this situation, he concludes that the document’s prohibitions on surrogacy would apply to the
adoptive mother, because she is becoming pregnant with a heterologous embryo with the intention of giving the baby to different parents.

Ultimately, Gormally’s major argument is that embryo adoption separates procreation from the marital relationship, and is therefore illicit. In embryo adoption, the woman makes, “a choice subversive to the dispositions required in any woman who chooses to allow herself to be made pregnant.”

Nicholas Tonti-Filippini makes similar claims in a 2003 essay on the topic of what he calls “embryo rescue.” He highlights Donum Vitae’s instruction that we need to consider not only the rights of the embryo, but also the fidelity of the marriage. In furtherance of his claim that embryo adoption is destructive to marital unity, Tonti-Filippini writes that it is the medical procedure that make the woman a mother and that, “becoming pregnant through [heterologous embryo transfer] … is an event from which her husband is, in effect, excluded.”

In addition to the idea that procreation is, in this case, separated from the marriage, Tonti-Filippini also focuses on the developmental continuum from fertilization to implantation to development, and makes a number of interesting claims. First, he claims that conception has not occurred until the embryo is implanted in the uterus. Further, he argues that the frozen embryo, more than being left in cryopreservation by its parents, in fact has no parents. Tying these claims together, he concludes that if conception is the fact of becoming pregnant, and becoming pregnant occurs when the embryo implants in the uterus, then an embryo which has been fertilized but not implanted in a uterus has not in fact been conceived. Because the fertilization occurs outside of the mother’s body, although she is biologically maternal, she cannot claim gestational maternity. In this case, Tonti-Filippini concludes that the embryo has no parents and has not been conceived in marriage.

The claims of both authors are unconvincing. Gormally is most concerned with the separation of procreation from the marital act, which may be a convincing rationale for the rejection of IVF techniques and ARTs. However, the question of embryo adoption is addressing a situation in which the procreation has already occurred, and a fertilized embryo is already in existence. The man and woman procuring the laboratory-based insemination of an ovum are the couple who have separated procreation from the marital act, and then compounded their error by leaving their offspring in a state of cryopreservation. However, the adoptive couple seeks only to remedy an unjust situation that has already occurred by adopting the embryo as their own child.

Gormally also argues that some types of embryo adoption, specifically those in which a woman gestates an embryo, gives birth, and then places the child up for adoption, is equivalent to surrogacy and is therefore illicit. If the first scenario is analogous to adoption, this scenario might be considered analogous to foster care, in which people care for a child until a permanent home can be found. This is certainly a more controversial (and less common) form of embryo adoption, but important points of consideration can be
found in the church teachings discussed above. First, *Donum Vitae*, notes that surrogacy is in part defined by the fact that a woman carries a pregnancy with a pledge to surrender the baby to the party commissioning the pregnancy. This is not the case in the embryo surrogacy described by Gormally, because the woman carrying the pregnancy is in fact gestating a baby that was abandoned by the party who commissioned the fusion of gametes and production of the embryo. While it is true that she is carrying unrelated, heterologous genetic material in her womb, she does not meet the church’s definition of a surrogate. Further, when answering the question of whether any procedures may be carried out on a frozen embryo, *Donum Vitae* allows for those that are directed toward the embryo’s “healing, the improvement of its condition of health, or its individual survival” (*DV*, I, 3). The intention of the woman in embryo surrogacy is specifically the individual survival of the embryo, which is allowable in the analysis of Ratzinger.

Tonti-Filippini is right to consider the fidelity of the marriage in his analysis of embryo adoption, but his conclusion that the process violates that integrity is mistaken. His claim that the woman becomes a mother by a medical procedure is a nuanced one, and deserves closer inspection. It is clearly true that, in embryo adoption, the genetic makeup of the embryo is not the same as the adoptive mother, and she therefore cannot claim to have genetic matrilineage of the embryo. But the term “mother” must be understood by Christians to mean more than simple genetic motherhood. The term also encompasses a much more philosophical understanding of motherhood that rests on the loving relationship between mother and child. This is why we consider a man and woman who have adopted children to be their father and mother; we understand that they are genetically unrelated, but the bond shared by parents who lovingly raise children is also considered, even by those children, to confer “motherhood”. An exemplar for Christians is found in the Holy Family, in which Mary and Joseph became the mother and father of Jesus not through genetic relationship or the marital act, but by a deeply spiritual relationship to the child Jesus. Their parenthood can only be interpreted as of the philosophical kind, rather than the genetic. Regarding Tonti-Filippini’s claim that an embryo procreated in a laboratory cannot be said to have parents, or even to have been conceived, it first must be stated that the embryo has clearly been procreated. If the procreated being is to be respected, it should be offered the chance at conception, birth, and life. Though the claim is difficult, if one accepts the claim that conception has not occurred for a frozen, procreated embryo, it might then be simple to claim that this state of affairs in fact advances an adoptive mother’s claim to maternity.

Many social injustices such as hunger and socioeconomic disparity cannot possibly be solved, but the church encourages charitable attention to them nonetheless.
Tonti-Filippini’s claim falls on the same logical continuum as a claim advanced by Mary Geach, who describes the artificial implantation of an embryo into a woman’s uterus as “allowing a carnal intromission of an impregnating kind.” By this description, she allows the comparison of artificial embryo implantation to the carnal act, and if the act is carnal, one should conclude that it violates the marital vow. However, Christopher Tollefsen provides a nuanced interpretation of what occurs in the marital act that allows a rejection of Geach’s claim. He writes that men and women perform [marital acts], but neither performs an act of making pregnant or becoming pregnant. … Why should we not say that the embryo itself … has made the woman pregnant? … The generative causality of the man and woman — the causality effected by the man’s sperm on the woman’s ovum — is at an end precisely because generation is over, and a new being with biologic causality exists.

By this argument, Tollefsen indicates that the act of receiving an embryo via a catheter inserted in the uterus does not, in fact, duplicate any part of the marital act, as making the woman pregnant is the action of the embryo, and not the man or the woman. This would, in his analysis, remain true whether the embryo entered the uterus via the Fallopian tube or via a catheter.

In his own essay on the topic, William E. May also makes reference to arguments put forth by Tonti-Filippini and Geach, and writes that although he agrees with the eloquent descriptions the aforementioned authors make of the beauty of the marital act, such descriptions are irrelevant to this debate because no marital act is involved in embryo adoption. Although May agrees that it is immoral for a child to be generated by a means other than the marital act, the question of embryo adoption is not one of generation; rather the question is how to treat an embryo which has already been procreated. He writes that, “The woman who chooses to transfer a frozen, orphaned, and unborn baby already generated in vitro from the freezer to her womb and to nurture it there as a means of protecting its life is definitely not choosing to generate a child by means other than the conjugal act.” Because of this, she cannot be said to be exercising unitive or procreative aspects of her sexuality extramaritally, or at all.

CONCLUSION
Most of this analysis has assumed that the church documents discussed above present accurate teachings, but the teachings have simply been misinterpreted as prohibiting embryo adoption. Dignitas Personae is certainly correct to note that, “the thousands
of abandoned embryos represent a situation of injustice which in fact cannot be resolved” (DP, II, para. 19; emphasis original). However, the insertion of this point in the discussion of embryo adoption seems to imply that embryo adoption cannot certainly hope to address this situation of injustice. In doing so, the document can be read as asserting that we need not try to remedy the injustice because there is, in fact, no adequate solution. However, if this implication was intended, it should be considered an error. After all, many social injustices such as hunger and socioeconomic disparity cannot possibly be solved, but the church encourages charitable attention to them nonetheless. Even adoption in the traditional sense is, “a remedial measure…for adoption often or even usually is due to forms of social injustice.”22 Despite this, and despite the lack of genetic kinship, the church encourages adoption as a charitable response to a situation of injustice.

Ultimately, it is most important to consider the clear church teaching that embryos, from the moment of their genesis, are owed the same respect and moral standing as any other human being. If this teaching is true, then embryo adoption can only be seen as consistent with church teaching, as the technique allows for protection of a human being without any violation of marital integrity. Ultimately, we can conclude that embryo adoption of previously created and cryopreserved embryos is consistent with church teaching, and should be allowed as a charitable response to an existing injustice.

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Creating Dialogue

1. What is the specific interpretive controversy that Malone is concerned about in this article? In other words, what do the church documents actually say about the embryo, its dignity, and the proposal of frozen embryo adoption?
2. Are there other ethical responses not mentioned by Malone that you can think of, by which we might approach this unjust situation, in harmony with the church’s moral guidance?
3. How would you explain the Church’s opposition to artificial interventions in reproduction, such as in vitro fertilization?
APPENDIX A: DIGNITAS PERSONAE, II, PARA. 19:

19. With regard to the large number of frozen embryos already in existence, the question becomes: What to do with them? Some of those who pose this question do not grasp its ethical nature, motivated as they are by laws in some countries that require cryopreservation centers to empty their storage tanks periodically. Others, however, are aware that a grave injustice has been perpetrated and wonder how best to respond to the duty of resolving it.

Proposals to use these embryos for research or for the treatment of disease are obviously unacceptable because they treat the embryos as mere “biological material” and result in their destruction. The proposal to thaw such embryos without reactivating them and use them for research, as if they were normal cadavers, is also unacceptable.

The proposal that these embryos could be put at the disposal of infertile couples as a treatment for infertility is not ethically acceptable for the same reasons which make artificial heterologous procreation illicit as well as any form of surrogate motherhood; this practice would also lead to other problems of a medical, psychological and legal nature.

It has also been proposed, solely in order to allow human beings to be born who are otherwise condemned to destruction, that there could be a form of “prenatal adoption”. This proposal, praiseworthy with regard to the intention of respecting and defending human life, presents however various problems not dissimilar to those mentioned above.

All things considered, it needs to be recognized that the thousands of abandoned embryos represent a situation of injustice which in fact cannot be resolved. Therefore John Paul II made an “appeal to the conscience of the world’s scientific authorities and in particular to doctors, that the production of human embryos be halted, taking into account that there seems to be no morally licit solution regarding the human destiny of the thousands and thousands of ‘frozen’ embryos which are and remain the subjects of essential rights and should therefore be protected by law as human persons.”
ENDNOTES
2 The document later defines the “very first instant” as “from the moment the zygote has formed.”
8 See https://www.nightlight.org/snowflakes-embryo-donation-adoption/.
9 Following this there are a number of questions regarding research on embryos which are not relevant to the present paper.
10 A secondary definition is similar to the first but includes the possibility that the pregnancy may be the result of an ovum from the woman carrying the baby and the sperm of a man other than her husband.
11 Please see Appendix A for the full text of Dignitas Personae, II, para. 19, which is the section most central to this essay.
12 This word, “intention,” is of key importance in Luke Gormally’s interpretation of the document.
17 Tonti-Filippini, “The embryo rescue debate,” 123.
22 Cahill, Theological Bioethics, 209.
Ars Moriendi and Society

Nathaniel Blanton Hibner, Ph.D.

As states continue to pass legislation legalizing physician-assisted suicide (PAS), it becomes ever more pressing to get to the heart of what is driving this movement. We have seen in surveys from the early adopter states some of the main reasons the terminally ill seek out PAS prescriptions. This is included in a variety of publications and will not be examined in depth in this paper. I wish to focus on three underlying forces that unfortunately fuel society’s drive towards the suicide solution. Then I will examine our faith community’s response, seeking out areas for further development. I hope that this article will continue the conversation regarding the ways the church and its members can assist those who are near the end of the earthly journey.

AUTONOMY

Autonomy in our society usually upholds one’s independence and freedom to choose. We see this understanding being used by politicians and media activists who promote PAS legislation. An editorial by the New York Times in September 2015 urged Governor Brown to sign the California End of Life Option Act. In this article, the editorial board praised the ability of taking “control of the timing of [one’s] death.” This line sounds familiar to the mission of the pro-PAS organization Compassion and Choices, which seeks to “increase patient control” and “access to all end-of-life options.” Control and access, power and options — these are the values promoters of these bills argue for and that have resonated in our society.

A major critique of this autonomy approach emerges when outsiders question whether PAS in fact promotes these desired outcomes. Cathleen Kaveny’s use of political philosopher Joseph Raz’s version of autonomy calls into question the desired effect of these laws. She rightly picks up the cry of most PAS supporters that these laws provide more autonomy for the terminally ill. However, she shows the ways that death with dignity legislation actually decreases a person’s autonomy. The inclusion of PAS as part and parcel of patient treatment choice could lead to the underdevelopment of other treatments, especially palliative care or hospice services: “The change in law might abate the urgency of providing other forms of end-of-life assistance.” It also inherently places a value judgment on those who choose to die naturally, or in this debate, “without dignity.” All of this could lead a person to choose death prematurely, therefore, undermining the state’s interest in protecting the vulnerable from coercion or manipulation. With autonomy as a rallying cry for pro-PAS activists, it is mandatory that any plan of action to counter PAS legislation address this concern.

THE FAMILY

Autonomy and family go hand in hand in this debate. David McCarthy speaks about the economic forces affecting the modern
family and the way in which society puts a high value on the independence of the family unit: “Rather than household management or filial duties, modern families have political and market relations at their center.” The wage earner is the spokesperson for the family since it is this individual who is the provider. The economic character of the family defines its relationship to society. Therefore, a family that does not seek welfare assistance and can contribute to the market is valued and upheld as an exemplary model. McCarthy even dives into the current family structure to show that children must also have a level of independence, learning “the standards of conduct,” and contributing to the betterment of the family itself.

These observations on the family reveal another layer of unconscious support for PAS at the end of life. Terminally ill patients already fear being a burden to their family. However, families themselves may desire to avoid being a burden to society, and therefore, decide to keep the situation internal. I believe that this could lead them to find solutions that would require the least assistance from the greater community, avoiding costly alternative options. Asking for financial support for hospice or long-term palliative care would reveal a weakness in the autonomous and independent family unit valued in contemporary society.

Lisa Cahill recognizes this dilemma as a failure of social justice for all, which especially affects poor communities. She observes: “The health care situation for disadvantaged populations is worsened by poverty and constraints on resources in the community as a whole; for individuals, it can also be exacerbated by communal expectation that the welfare of one should give way to the needs of the family.” This communal expectation is similar to the personal autonomy situation, where the need to ask for help, even from one’s family, is seen as a loss of independence — loss that is undesirable.

CHRISTIAN DUTY TOWARDS BURDEN
The Catholic tradition has tended to place a high value on bearing suffering for others. The obvious example is that of Christ who, according to some Christologies, took upon himself the sins of the world. In one way, Jesus’ example can be viewed as a person who conscientiously chose to suffer rather than take the “easy” way out. However, in a more inherent way, Jesus reveals the model of alleviating others’ pain through personal suffering, through personal choice. By extension, it is possible that dying patients could then find value in making the decision to end their lives deliberately, as if this would eliminate the burden on their family members. “I will choose when to end my life, so my family does not have to.”

We can see this idea borne out in Catholic writings on motherhood and the expectations of a dutiful wife. JoAnne Marie Terrell, for instance, writes a chapter titled, “Our Mothers’ Gardens.” In it she describes the way that certain Christologies have sadly fueled the continued oppression of black women in America. She concludes her reflections on the power of this tradition by relaying the story of her mother:
Although I may never be required to give up my life for the sake of my ultimate claims, the peculiar efficacy of my mother’s sacrifice as well as the Christian story prevent me from discarding the idea altogether, particularly the notion of sacrifice as the surrender or destruction of something prized or desirable for the sake of something with a higher claim …

These models of virtue indirectly promote the idea that women in particular ought to sacrifice their own bodies and dreams for the betterment of the family. Could then the church’s upholding of such behavior promote the ultimate sacrifice of a terminally ill patient for the sake of their family? Could these Christian models actually increase Christian willingness to actively embrace and pursue a kind of martyrdom?

SOLUTIONS
Ars Moriendi
Many theologians draw upon the tradition of ars moriendi to address the social promotion of PAS legislation. One such author is Christopher Vogt, who devotes an entire book to the subject. In it, Vogt highlights certain virtues in the tradition that one must develop in their lives in order to face death in a correctly Christian way. He sees a strong connection between ars moriendi (the art of dying) and ars vivendi (the art of living). Vogt writes, “It is by a lifelong effort to nurture faith, hope, patience, compassion, and all the virtues of the good Christian life that we best prepare ourselves for the time of dying.”

Cardinal Bernardin chose to see his death as another leg of the trip, extending “beyond mortal existence to eternal life.”

This pairing of the two “arts” stems from the teaching of virtue ethics. Virtue ethics promotes the idea that all actions have a shaping effect on the actor’s character. Therefore, virtuous actions create a virtuous person, sinful actions create a sinful person. To become a virtuous person “it is necessary to engage consciously in practices that concretize the good in order to … move oneself closer to embracing the good life.” Vogt and the tradition understand that to help people face death they must have the virtues of hope, compassion, and patience. These three virtues provide the individual the proper inherent disposition to see death not as mere suffering, but as a part of our Christian journey. It is a personal development that hopefully will reap rewards at the end of our days.

Cathleen Kaveny offers a similar solution. She draws upon an exemplar of a good Christian death — Cardinal Joseph Bernardin — to reveal to the world the power of faith and an alternate approach to death. Using his last book, The Gifts of Peace, in which the Cardinal reflects on his diagnosis, treatment, remission, and then the return of cancer, Kaveny wants to show a truly Christian manner of dying. She argues that Cardinal Bernardin’s example can serve as a “framework [that] can facilitate the exercise of
Razian autonomy on the part of dying patients, and solidarity on the part of those surrounding them.”10 Cardinal Bernardin chose to see his death as another leg of the trip, extending “beyond mortal existence to eternal life.”11 He chose to treat his life as a steward whose “ultimate nature and purpose are determined not by [himself] but by the creator … ”12 This gave him true freedom: “the freedom to let go.”13

The manner in which he chose to accept his final years allowed Bernardin the ability to overcome his suffering by staying true to his life’s mission as pastor. The writing of his personal story gave him the opportunity to recognize the power he still had in providing positive change in another person’s life. This is the example of a more truly “autonomous” individual who reintegrated his torn self and gained a new narrative. It is a call for all of us to reflect not only on the life we wish to live, but also the death we wish to experience.

Falling Short
Even though I as a Christian find these arguments very convincing for my own life and I will take the lessons they teach into my personal vocation, I do not believe they address all the underlying problems. Kaveny’s use of Cardinal Bernardin rightly, and I believe successfully, counters the pro-PAS conversation on autonomy and death-with-dignity. The example reveals a more Christian and, hopefully, a better definition for autonomy. The story also urges the onlooker to witness a dignified death that did not utilize PAS, therefore undermining the very title of these laws. Good as such outcomes are, they do not go far enough to redress the deeper, socio-structural problems that make PAS seem like a fitting solution to the challenge of dying well.

Similarly, Vogt’s use of ars moriendi also addresses the autonomy and dignity debates. However, like Kaveny, he does not recognize the power of social structures to force people to end their own lives. Furthermore, this tradition can also be used to justify the third underlying force mentioned above – Christian duty towards burden. Ars moriendi is a very personal experience; one must shape their own dispositions in order to have the strength needed to face their death. It places a great burden on the individual and some may deny its appeal, as if the “art of dying” is synonymous with telling them just to bear it. For example, Vogt includes a passage from William Perkins, an ars moriendi thinker:

He that would be able to beare the crosse of all crosses, namely death itselde, must first of all leare to beare small crosses, as sicknesses in body & troubles in mind, with losses of goods and of friends, of good name, which I may fitely tearme little deaths . . . wee must first of all acquaint our selues with these little deaths before we can well be able to beare the great death of all.14

Personal fortitude at death can only lead us so far. To overcome the pressures on family and the inability to humbly ask for help, social views on weakness and burden must be dramatically changed.
“What constitutes a good life in this community, what constitutes a good way to take one’s leave from life, and what our collective obligations are to those in the midst of their leave-taking.”

— Cathleen Kaveny

Even though Vogt goes on to counter this passage with a more updated definition of patience, it nevertheless is a quote from an original ars moriendi writer. The idea that a good Christian will bear the “great death” by bearing a succession of small deaths makes it seem saintly to face hardships alone. This passage does not value asking for help or seeking someone to lean on. It does not ask society to change health services and financing. It is a theme that undergirds the tradition, and unfortunately, is one that may prevent people from using palliative and hospice services.

FINDING ANSWERS IN THE COMMUNITY

When we take seriously the concerns of the patients along with the underlying forces promoting PAS, we realize our solutions must be broader. Personal fortitude at death can only lead us so far. To overcome the pressures on family and the inability to humbly ask for help, social views on weakness and burden must be dramatically changed. The authors under review do have some insights with which to start such a process of revision, especially Kaveny’s defense of solidarity and Vogt’s promotion of compassion.

Kaveny addresses the desire of supporters to create an option that would alleviate one’s suffering. She draws from the work of Eric Cassell. Suffering is for Cassell “‘the distress brought about by the actual or perceived impending threat to the integrity or continued existence of the whole person.’” Again, she places this conception within the Razian definition of autonomy. Kaveny writes, “In Raz’s terms, then, suffering is such a wrenching experience because it disintegrates previously autonomous persons, cleaving them from the plans and purposes with which they have defined themselves as part-authors of their own lives.”

Where does this lead us? If we hold a Razian sense for autonomy, and we believe that suffering is something which diminishes a person’s autonomy, then we must find “a way forward toward reintegration, toward a new life that somehow also incorporates a narrative about the old life.” We must give people the ability, the opportunity at least, to regain personal identity and mission. Using the writing of Bernardin, Kaveny puts it this way: “We are called to be one another’s keepers and to bear one another’s burdens as brothers and sisters in Christ.” We are called to live in solidarity. “By standing with those who suffer, we can potentially help them to reconstruct their identities, find a new wholeness in their lives, and ultimately transcend the loss of their previous integrity.”
Kaveny then redirects our focus to the fundamental questions in this debate, namely: “What constitutes a good life in this community, what constitutes a good way to take one’s leave from life, and what our collective obligations are to those in the midst of their leave-taking.”

These are questions that a community must answer, not only an individual. It requires strong, but productive debate and a great deal of reflection.

Christopher Vogt does provide some communal solutions in the final chapter of his book. He recognizes that:

So far [his] advice [is] directed toward individuals … But a change in consciousness within any number of individuals will not be enough to transform the contemporary experience of dying from an unspeakable horror into an endurable tragedy. The efforts of individuals must be supported by communal practices in order to bring about noticeable change.

Regarding Christian communal practices, Vogt wonders whether parishes could create volunteer organizations that would provide company to those at the end of life. These individuals would assure that a person remains connected to the community of the parish even as their souls begin to separate from this world. In my opinion, such a practice could help to witness before the world the virtue of mercy, such as defined by James Keenan: to enter into the chaos of another.

Families, however, are not the only ones required to help alleviate the burden of death.

Our broader relationships as friends, co-workers, Christian brothers and sisters, and neighbors ought to fuel a sense of duty and courage to enter into that chaos and give our support to those in their last stages. Kaveny, Vogt and other virtue ethicists urge for personal practices that would help develop the inner dispositions to face death. This same power of practices could then be extended to help develop social virtues of mercy, solidarity, and charity in the wider community.

**PRACTICES: FAITH AND SOCIETY**

So what would this look like practically? Lisa Cahill knows the challenge this question entails when she states, “Modifying social practices toward wise and just solidarity with the dying demands the imaginative and practical introduction of a new horizon of meaning regarding these life experiences and events.”

We as Christians, and fellow humans have the charge to find new and creative paths towards changing society’s approach towards death.

One obstacle to this change in modern times is the rise of death in hospitals. Death has become separated from our daily lives and therefore remains a mystery. It is constantly portrayed as an individual agony and personal suffering which needs to be sequestered or otherwise might infect the wider community. In response, Cahill praises the rise of hospice care as recognizing the needs of the dying and the duty of the living. Perhaps re-incorporating death into the mainstream, while giving recognition towards the hospice movement, would allow people to become more familiar and hopefully more comfortable approaching a dying individual. Vogt’s suggestion of creating a hospice care team seems like a brilliant idea for
re-integrating death, a dying person, and the parish community.

The Christian sacraments can also help to re-incorporate the dying with the parish. Groups of individuals can go with the priest to give the anointing of the sick. Parish leaders can be there for the grieving family. We have already begun to once again include the sacrament of baptism into the Sunday liturgy. Perhaps more could be done with the passing of a parish member beyond simply giving times for the funeral and wake. Such a practice may include a short eulogy, pictures of the deceased near the altar, or a prayer of thanksgiving for their entering into the kingdom of heaven. These would help recognize the value of the person to the broader parish community, as well as provide resources for those who are nearing the end of their lives.

Finally, we need to change the view of autonomy, especially the negative judgment on burden and asking for help. I am thinking about the parable of the Good Samaritan. This story in Luke’s Gospel often acts as an example for the Catholic health care ministry. However, we always focus on the Good Samaritan and the manner in which he helped the stranger. What I find more fantastic in this story is the way in which the robbed man had the humility to allow a stranger to help. Could we, in our society, praise such behavior? Could we imitate the beaten man in asking a stranger for aid? Unfortunately, I think the answer is currently no. This needs to be changed if we want people to use the resources that we hope will one day be available to all.

**CONCLUSION**

The current legal and political debate on physician-assisted suicide does not mirror the real-world experiences of the dying. Society’s views on autonomy, the church’s teaching on suffering and burden, and the heroic nature of independence are currently fueling the support for these bills. The ars moriendi tradition being upheld today requires a broader sense of community. The problems inherent in our society cannot be properly addressed by only changing the inner disposition of the dying towards a greater cultivation of virtue. Instead, we must look towards broader social and systematic changes. It is when society can courageously enter into the chaos, extend its hand of support, and encourage the dying to take hold that will we truly overcome the darkness of death.

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*nhibner@chausa.org*
Creating Dialogue

1. How would you summarize the contrasting accounts of personal autonomy discussed in this article? What does autonomy mean within modern and popular culture, what does it mean within the Christian faith community?

2. Do you find Hibner’s suggestion compelling, that we should all be more concerned to retrieve the “art of dying”? What, if anything, would make this concept more compelling for you personally? What would make it more compelling for contemporary society?

3. What role do you think the family currently plays in mediating the dying process? What role should the family play?

ENDNOTES

1 Compassion and Choices, https://www.compassionandchoices.org/who-we-are/about/
4 Ibid., 77.
5 Lisa Cahill, Theological Bioethics (Washington: Georgetown University Press, 2005), 118. My emphasis.
7 Christopher Vogt, Patience, Compassion, Hope, and the Christian Art of Dying Well (New York: Bowman & Littlefield), 131.
8 Ibid., 4.
9 Ibid., 4.
10 Kaveny, Law’s Virtues, 143.
11 Ibid., 144.
12 Ibid., 145.
13 Ibid., 146.
14 Vogt, Patience, 131.
15 Ibid., 152.
16 Ibid., 153.
17 Ibid., 155.
18 Ibid., 145.
19 Ibid., 173.
20 Ibid., 175.
21 Ibid., 136. My emphasis.
23 Cahill, Theological Bioethics, 120.
24 Ibid., 121.
Using REDCap to Track Ethics Consults

Becket Gremmels, Ph.D.

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DATA ANALYTICS AND ETHICS CONSULTS
Any clinical service or committee needs a good understanding of what it is doing in order to determine how to do it better or where to direct its actions. A clinical ethics service is no different. Numerous articles describe the importance of tracking and analyzing data related to ethics consults.1 At least two Catholic systems have described the database used to track their ethics consults.2 One uses Microsoft Access, which can mean only one computer can be used for entering data unless a web-based platform is created, which can be done internally but takes time and funding. The other uses an internal online interface custom-built by the system’s IT department, which may be time-consuming, cost-prohibitive for many ethics departments or ethics committees, and unlikely to be a high-priority for many IT departments. To overcome these obstacles, CHRISTUS Health uses REDCap to track ethics consults. The following description of that database and customized tracking project will likely be of interest to ethics committees throughout Catholic health care.

RESEARCH ELECTRONIC DATA CAPTURE (REDCap)
REDCap is a customizable database that allows users to track data in multiple formats.3 The software has an online interface that is accessible from any computer or device with internet access. REDCap was built at Vanderbilt University and is completely free to not-for-profit organizations. The only costs to CHRISTUS Health were finding space on internal servers and the time it took the IT department to vet and install the software. Originally created to track data from human subjects in clinical trials, it is currently used by more than 3,320 organizations in 129 countries, which REDCap calls “partners.” Currently, at least 10 Catholic health systems are listed as partners on the REDCap website. (See Table 1) Some are listed at the system level, like CHRISTUS Health, others are listed through a subsidiarity region or legacy organization, like Saint Thomas Health, which is part of Ascension Health, or CHI, now part of CommonSpirit Health.4
Many REDCap partners are healthcare organizations. Since REDCap was designed to store patient data, it is HIPAA compliant. Although it can interface with electronic medical record platforms, we have not yet pursued this feature at CHRISTUS Health. Due in part to HIPAA and data security concerns, CHRISTUS Health chose to store all tracked data internally on our own servers. REDCap does offer to store data on its servers for a fee.

As a customizable database, REDCap can be designed by its users to track almost anything. Users can create unlimited “projects,” which is what REDCap calls the databases, and each project can carry an unlimited number of fields, i.e., questions that users are asked when entering data. The fields can consist of a short answer, free text boxes, multiple choice with radio buttons or checkboxes, drop down menus, yes or no, true or false, and a sliding scale, among others. The content in free text boxes can later be searched to identify certain elements related to cases. For example, if a free text box is used to describe consults, a search can find all entries that mention “brain death” or “feeding tube.” Other fields can be used to embed video or audio files, link to other websites, or allow the user to upload a file. Fields can also be required so a response must be entered in order to mark the consult complete. Using logic, fields can be hidden or shown, e.g. one field might only be visible based on the answer in another field, or the possible answers in one field might change based on the answer to another field. Since the fields are entirely customizable regarding content of the questions and possible answers, they can be written in other languages as well. REDCap also has an option to view background information in Spanish. Since CHRISTUS is an international health system, with 15 hospitals and 15,000 associates in Latin America, this was a significant benefit to using REDCap.

A substantial benefit of REDCap is that the controlling user can make edits or updates to the data fields on their own, without the

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<th>Table 1</th>
<th>Catholic Systems Listed as REDCap Partners</th>
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<td>• OSF Healthcare</td>
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<td>• Providence-St. Joseph Health</td>
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<th>Table 2</th>
<th>Appealing Features of REDCap</th>
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<td>• Free to non-profit organizations</td>
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<td>• Customizable</td>
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<td>• Accessible from any computer or device with an internet connection</td>
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<tr>
<td>• Various levels of user access</td>
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<tr>
<td>• User friendly to enter data and to customize</td>
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<tr>
<td>• Free app for mobile devices</td>
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<td>• Commonly used in healthcare</td>
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<tr>
<td>• HIPAA compliant</td>
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<tr>
<td>• Already available at many Catholic systems</td>
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involvement of IT. Creating, altering, or updating the data entry screens is user friendly and requires little to no IT expertise. This means that an ethicist, mission leader, ethics committee chair, or whoever is in charge of the database can alter it on their own without submitting an IT ticket. In CHRISTUS, an ethicist, or another superuser, can make any needed updates on their own, usually within an hour of being requested. In addition to its database feature, REDCap can also be used to create surveys, similar to SurveyMonkey®, Qualtrics, or Google Forms. Once created, the database or survey can be downloaded into a CSV file and shared with other institutions. This file contains only the customized fields, no data, and can be uploaded into REDCap, which then allows the second institution to have the same customized fields or to further customize the fields to meet their own needs.

Users can be granted various levels of access to data and features within REDCap. Limitations on access include only data entry, only entering some kinds of data, creating reports, viewing certain reports, editing data, updating data, deleting data, among others. Each user’s level of access can be customized exclusively to them, or they can be assigned to a role with designated levels of access and authority. Consequently, ethics committee members, ethics committee chairs, ethicists, mission leaders, etc., can have different levels of access to data, data entry, reports, etc. Adding new users does not require any software installation on their computer; no licensing needs to be sought from REDCap and no fee paid per user. The number of potential users is unlimited. Access can also be limited by Data Access Groups. Users can be assigned to a Data Access Group, which means they can only view data entered by people in that group. A large health system could, for example, create a Data Access Group for each hospital or region so users could only view data in their hospital or region.

REDCap also offers a free app for use on smartphones and tablets, which is available on Apple, Android, and Microsoft devices. The app provides the exact same customized queries and fields as the online interface. This allows data to be entered at any time, quickly, and easily. Small things like this ease of data entry encourage ethics committee members to enter data. As these people are often volunteers with full-time jobs, they are always pressed for time and have many pressures pushing against the consistent and accurate recording of consult data.

Once data is entered into REDCap, it can be viewed through the reporting feature. Reports are customizable, meaning they can show responses to any combination of fields and can be filtered out by any combination of fields. In other words, a report can be created to show all data related to all consults in a region, or the reasons for consults that were requested by nurses, or the discipline of everyone who requested a consult in the ICU at a particular hospital during the past month. New reports can be created by any user who has that level of access. Once created, a report is saved until it is later modified or deleted by its creator. The creator can share the report with any combination of users or keep it private for themselves. Reports can be viewed as a table, a bar graph, or a pie chart, or they can be exported into multiple formats for further analysis, including Excel, SPSS, SAS, and Stata, among others. Note that creating reports,
downloading reports, or collecting data for research purposes through REDCap requires IRB approval.

For all its benefits, CHRISTUS has encountered three drawbacks to REDCap so far. First, the reporting feature is not as user friendly as it could be. Adding filters and criteria when creating a new report is somewhat complicated and some users report difficulty doing so. The graphs are easily viewable but data labels are not automatically created. Thus, to prepare graphs and charts for presenting data, the report must be downloaded to Excel or another format. Second, a field cannot be repeated indefinitely. This would be helpful to allow an indefinite number of repeated entries of a certain data point. For example, some
ethics consults involve multiple issues and it is difficult to set a hard limit on how many issues to allow users to enter. Indefinite repetitions of a field would permit the user to enter as many reasons as they see fit. Unfortunately, we were forced to set a definite limit (see discussion below). Third, since REDCap is free, there is minimal IT support from REDCap itself. Unlike other software, REDCap does not have a help line to fix errors when something goes wrong. However, there is a vibrant online community of IT personnel at REDCap partner organizations who help each other out as needed. There are also weekly and monthly calls for IT personnel to ask for help from each other. One potential drawback for other health systems is the vetting process by the IT department. This may not be a high priority for some IT departments, which could cause delays or even lead to cancelling installation of REDCap altogether.

CHRISTUS Health Ethics Tracker in REDCap
CHRISTUS Health began beta-testing our Ethics Tracker project in REDCap in September 2017. Each region in CHRISTUS selected two to three members of their Ethics Consult Team to serve in the beta test group for about six months. After making several changes

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**Figure 2**
CHRISTUS Health Ethics Tracker – Bottom of Screen

- **Consult Type**
  - General Adverisement: Offering an opinion or clarification for informational purposes that will not form the basis for altering a specific patient's plan of care.
  - Policy Clarification: Responding to questions related to institutional policies and/or the ERGs.
  - Patient-Care Consultation: A process of gathering facts, engaging various stakeholders, and identifying and applying norms in order to arrive at a recommendation intended to influence a specific patient's plan of care, usually but not necessarily documented in the patient's record.
  - Retrospective Case Analysis: Post-Discharge review of a specific case for the purpose of improving existing care processes.

- **Primary Consult Reason Category**
- **Additional Consult Reason Category**

- **Consult Narrative**
  - This is optional. Briefly describe (1-6 sentences) the background of the consult that led to the requestor asking for the consult. Consider completing if the consult has unique ethical components.
  - Please make sure your description is de-identified. Do not put any information that can identify the patient, such as the name of the patient, physician, nurse, or other provider.

- **Consultant’s Recommendation**
  - This is optional. Briefly describe (1-6 sentences) your actions, recommendation, and what resolution (if any) occurred. Consider completing if the recommendation or resolution has unique or nuanced ethical components.
  - Please make sure your description is de-identified. Do not put any information that can identify the patient, such as the name of the patient, physician, nurse, or other provider.
based on their suggestions, we went live with Ethics Tracker in April 2018. As of March 2019, 102 users are registered and collectively have entered 260 clinical ethics consults. For our ministries in Latin America, we have a draft translation of the Ethics Tracker project in Spanish which is currently being reviewed prior to beta testing.

In designing our Ethics Tracker project in REDCap, we took several steps to simplify data entry in order to encourage it. First, we picked field types that permitted quick identification of the desired option, so all the required fields are drop-down menus except two (Date of Consult Request and Response Date) which have the option of calendar pop-ups. (See Figure 1 and Figure 2) Second, we hid many fields with logic which only pop up when necessary. For example, if the user selects physician as the person who requested the consult, a hidden field is shown that asks the physician’s specialty; otherwise that field is hidden. Third, some fields are always hidden and completed automatically. For example, the user’s name is automatically entered into a hidden field to save the user from having to enter it. Fourth, we limited the required fields to only what is absolutely necessary. Unlike some tracking software, we do not track patient-specific data like age, race, gender, insurance status, etc. The only patient data the user needs to enter is the patient’s MRN and Encounter Number (if applicable), and we run a report in the EMR at a later time (usually once a year) to collect the other data based on the MRN and Encounter Number. For Reason for Ethics Consult, we limited it to five possibilities, but only the first one is required. At most, we only require 15 data fields to be entered before saving. In total, once a user becomes familiar with the process for entering a consult, it takes less than four minutes to complete the required fields. Lastly, to facilitate and encourage data entry, users can request access to Ethics Tracker through the REDCap mobile app. The fields and format are exactly the same as the online version. (See Figure 3)

We have set up a number of standard reports that all viewers can see at any time. (See Figure 4 and Figure 5) Only mission leaders, ethicists, and Ethics Council Members (all Ethics Committee Chairs and Co-Chairs) can create other reports. Only these users can download data into Excel or another format for further analysis. This enables the Ethics Consult Team
The Team might also ask the entire Ethics Committee for input or assistance developing or deploying a tool or resource in response to those trends. For example, one region noticed a significant number of clinical ethics consults related to identifying the appropriate surrogate decision maker for a patient who lacks decision-making capacity. They worked to create a color-coded informational sheet that outlined the hierarchy for surrogate decision makers per state statutes. This sheet has since been adapted to other states and deployed to all CHRISTUS hospitals in the United States.

In addition to tracking clinical ethics consults, we also use REDCap to track organizational
Figure 5
Clinical Ethics Consult Report – Graph View

Setting of Consult Request In what unit or setting did the consult arise? If this is a Patient Care Consultation, what unit was the patient in when the consult was requested? (setting_of_consult_request)  Refresh Plot  |  View as Pie Chart

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Counts/frequency: Ambulatory Surgery Center (0, 0.0%), Assisted Living (0, 0.0%), At Home - Health Plans (0, 0.0%), Behavioral Medicine (0, 0.0%), Burn Unit (0, 0.0%), Cardiac Unit (0.0%), Emergency Department (0, 0.0%), Free-Standing ED (1, 10.0%), GIP Hospice (0, 0.0%), Home Hospice (0, 0.0%), Inpatient Hospice (0, 0.0%), Intensive Care (ICU) (5, 50.0%), Labor and Delivery (1, 10.0%), Long Term Acute Care Hospital (LTACH) (0, 0.0%), Long Term Respiratory Unit (0, 0.0%), Medical Surgical Unit (1, 10.0%), Memory Care Unit (0, 0.0%), Mother/Baby Unit (0, 0.0%), Neonatal Intensive Care (NICU) (0, 0.0%), Neurology/Stroke Center (0, 0.0%), Oncology Unit (1, 10.0%), Operating Suite (0, 0.0%), Outpatient Clinic (0, 0.0%), Palliative Care Unit (0, 0.0%), Pediatric ICU (0, 0.0%), Pediatric Unit (0, 0.0%), Post-Operative (0, 0.0%), Post-Anesthesia Care Unit (PACU/Recovery) (1, 10.0%), Radiology (0, 0.0%), Rehabilitation Unit (0, 0.0%), School-Based Health Center (0, 0.0%), Skilled Nursing Facility (0, 0.0%), Surgical Unit (0, 0.0%), System Office (0, 0.0%), Transplant Unit (0, 0.0%), Trauma Unit (0, 0.0%), Urgent Care (0, 0.0%), Women’s Health (0, 0.0%), Special Care (0, 0.0%)

CHRISTUS Santa Rosa (christus_santa_rosa)  Refresh Plot  |  View as Pie Chart

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Counts/frequency: CHRISTUS Physician Group (0, 0.0%), CHRISTUS Santa Rosa Hospital - Alamo Heights (0, 0.0%), CHRISTUS Santa Rosa Hospital - Medical Center (3, 30.0%), CHRISTUS Santa Rosa Hospital - New Braunfels (1, 10.0%), CHRISTUS Santa Rosa Hospital - Westover Hills (6, 60.0%), The Children's Hospital of San Antonio (0, 0.0%)
ethics consults, ethics education events, and uses of the CHRISTUS Health Values Based Decision Making Process. Each kind of entry has a separate screen. All users have access to clinical ethics consults, but only some can access the other three. Outside of ethics, the mission department has considered REDCap to track uses of Critical Incident Stress Management. It could also be used to track spiritual care consults, conduct satisfaction surveys for people who request ethics consults, or any number of other services or procedures.

A PATH FORWARD?

Since REDCap is free, easy to use, customizable, and easy to share, it holds serious potential as a vehicle to standardize data collection and analysis of clinical ethics consults throughout Catholic health care and beyond. At least one ethicist has called for such standardization. This report of REDCap serves to reiterate that call. In future publications, we will describe how using REDCap to track consults contributed to our efforts to show the return on investment (ROI) that clinical ethics consults provide to the organization. A standardized, user-friendly template for showing that ROI for ethics consults within Catholic health care would go far in justifying more dedicated resources to ethics that many ethicists anecdotally say they need. The Palliative Care Quality Network (PCQN) and the Center to Advance Palliative Care (CAPC) have these tools for palliative care, and many hospitals have used it successfully to expand their palliative care programs.6 This success is also possible for ethics, but we first need to achieve some minimum standards on what data to gather. REDCap offers a good opportunity to take a first step down that path.

ENDNOTES


3 To find out more about REDCap, visit www.project-redcap.org.

4 To search for health systems that have REDCap already, and to see the names of the people at each organization responsible for REDCap, visit www.project-redcap.org/partners.

5 Since these entries can contain PHI, depending on what fields are created and what information is entered, users should have a justifiable work-related reason to conduct searches and searches should be limited to what is minimally necessary to meet the need. Justifiable reasons could include process improvement efforts as part of a Next Generation Ethics Committee, education of self or others quality improvement efforts, or assessing the quality of the content of consult documentation, among others.

Ethical Currents:
An Aesthetic Response: Job, Suffering, and the Healing Power of Divine Beauty

Alec Arnold, Th.M., Ph.D.(c)

Author’s note: This article is an edited form of a paper originally presented at the Conference on Medicine and Religion, “My Pain is Always with Me: Medicine and Faithful Responses to Suffering,” Duke University, March 29-31, 2019. I am grateful to that audience for its interaction, as well as to the editors of HCEUSA and Karla Keppel for helpful comments on a more recent draft of this essay.

The Book of Job has long served as an invitation for reflection upon some of the deepest existential questions affecting the human heart, especially about the nature and purpose of human suffering, loss, and pain. According to Jewish literary scholar, George Steiner, Job's unfolding demand for nothing less than a divine response to his plight intimates at least three categories of discourse with which most of us are likely familiar. First, says Steiner, “Job's inquiry is ontological,” in the sense that Job “questions the being of Being,” levelling doubts about the goodness of reality itself.1 Second, Job's inquiry is epistemological, as Job longs for deeper knowledge and insight, seeking to clear away the confusion about why his Creator would allow such calamities. Finally, says Steiner, the framework of Job's questioning is explicitly theological, since Job is ultimately led to raise his complaint against God himself, the One who made him and brought him to being.

Yet, as Steiner observes, when the living God finally does appear in the book's climax, God's response to Job will have nothing to do with any of these all-too-human discursive categories. Instead, Steiner writes, “[God's] reply is that of a Maitre brandishing the catalogue raisonné of his œuvre. Its category is that of the aesthetic.”2

My purpose in this essay is to explore this “aesthetic response” of God to Job in more detail, and to consider the practical relevance of “theological aesthetics” in the clinic today. God's response to Job exhorts all of us, especially those engaged in medicine, to embrace a more capacious interpretation of the sufferer's process of healing in which the spiritual senses should be expected to be as active as the bodily senses. Job's experience suggests that perceptual encounters with Divine Beauty can be part and parcel of a profound transformation within the human creature, whereby a new relation to this worldly suffering is possible. In considering the practical implications of such a theology for medicine today, I will hardly conclude that health care providers are somehow directly responsible for inaugurating these kinds of spiritually transformative moments for their patients and families. Surely, though, there is more we can do to create the occasions for such transformation in our various centers of healing. I will offer a few suggestions in this regard before my conclusion.
JOB AND THE LIMITS OF REASON

By and large, previous attempts to read Job for the sake of informing clinical responses to suffering have focused on how clinicians specifically should approach the phenomenon of communicating with patients who are facing difficult diagnoses. Attention has often been drawn to Job’s conversations with his friends, who are said to supply several examples about what not to do in the course of clinical consultation — at least not if we hope to express genuine concern for the whole person before us.

For example, Fr. Joseph Tham recently turned to Job in an article aimed at carving out a space for spirituality and religious hope to be reintroduced to the contemporary, “secular” hospital setting. Tham highlights the discourse of Job’s three friends (Eliphaz, Bildad, and Zophar), and the friends’ collective failure to offer any meaningful insight to Job’s existential dilemma. In particular, Tham notes their tendency to avoid any direct contact with God, since they prefer instead to speak about God in the third person, but never invoke God directly. Only in the case of Elihu, the fourth and last speaker, do we find a willingness to exalt God paired with a more nuanced approach to questions about divine justice and Job’s suffering, such that, according to Tham, Elihu “plays a prophetic role of speaking on behalf of God, … preparing him for God’s subsequent theophany.” For Tham, Elihu succeeds where the others fail, and we are given to learn how spiritually-minded clinicians should use speech and language strategically, making space for a divine encounter similar to the experience of Job. Accordingly, when Tham turns to consider the crucial moment of encounter between God and Job, he again puts the spotlight on the communication dimension, this time discussing the effect of God’s own discourse with Job — the way in which God’s questions seem deliberately designed to procure Job’s “stupefaction.” Tham concludes that the point of God’s appearance is to cross-examine Job’s intellect and to humble his reason, chastening his attempt even to grasp at God’s purposes behind the scenes.

According to this overall reading, the Book of Job underscores how the reality of suffering utterly boggles the human capacity to reason one’s way through it. As Tham puts it, Job shows us how “suffering is a reality that is not questioned but affirmed. No answer is offered at the end of the book; God’s presence and omnipotence are sufficient.” Thus we do well, says Tham, to learn from Job: accept the limits of our own finitude, humble our reason, and embrace the mystery of suffering by welcoming God into it.

To be sure, these are important reminders, but there is arguably something missing from this predominantly logocentric exegesis, so concerned with the discursive aspects of our experience with suffering and our communication with sufferers. What seems to be missing is a deeper consideration of Job’s final transformation, which, recalling Steiner, has more to do with Job’s aesthetic, perceptual confrontation with God in creation than it does with the humiliation of reason per se. Job may indeed be seeking a divine response to his various levels of questions (i.e., the ontological, epistemological, and theological), but these latter forms of analysis are not what finally bring Job to that pivotal moment of metanoia. Rather, it is God’s “aesthetic response” that ushers Job into a new order of perception,
which is at the same a veridical experience of healing for Job, at least in the spiritual and existential sense. Having perceived a God made visible, Job’s own senses are transformed; he is given a new relation to his plight, precisely through being given a new relation to God. Before continuing in this direction more explicitly, though, I should explain what I mean by suggesting we read Job through this lens of “theological aesthetics.”

JOB AND THE RHETORIC OF DIVINE BEAUTY

In referring to theological aesthetics, I am appealing most directly to the work of twentieth-century Roman Catholic theologian, Hans Urs von Balthasar (d. 1988). Balthasar’s version of theological aesthetics represents a particular attempt to curb the effects of Kantian philosophy, which effectively solidified the broader Enlightenment tendency to separate our perceptual apprehension of reality as such — i.e., the knowledge gained by direct, sensory experience — from the conceptual knowledge of reason’s operations and our powers of reflection. Put differently, Kant’s philosophy erected an ostensible barrier between our perceptions of the natural world “out there” and our internal constructions of the same. Consequently, said Balthasar, the premodern sense for beauty — as an objective, ontological facet intrinsic to reality as such, the perception of which can rapture us in a participation with something truly transcendent — sadly collapsed in the modern period, becoming merely a function of one’s individual sense of “taste.”

Balthasar’s theology was largely concerned with remedying this situation by provoking contemporary people into a more comprehensive sense of beauty in this more transcendent dimension. He urged, for instance, that our capacity to perceive and respond to inner-worldly beauty is in fact an analogy of our capacity to perceive and respond to God’s own self-revelation. Missing out on such a crucial connection (between beauty and revelation), he opined, was spiritually fatal. As he puts it, “We can be sure, that whoever sneers at [Beauty’s] name as if she were the ornament of a bourgeois past — whether he admits it or not — can no longer pray and soon will no longer be able to love.”8 In another place he puts it this way, “An apparent enthusiasm for the beautiful is mere idle talk when divorced from the sense of the divine summons to change one’s life.”9 Obviously, Balthasar is not referring to beauty here in some drippy, sentimentalized, romantically emotional sense. Instead, for Balthasar, the perception of genuine beauty is nothing less than an existential encounter with the divine, which quite properly changes us in the moment of its encounter.

More recently, Eastern Orthodox theologian David Bentley Hart has rearticulated these same ideas but contextualized them within our postmodern context. In his book, The Beauty of the Infinite: The Aesthetics of Christian Truth, he argues that, however forcefully postmodernity has sought to deconstruct the legitimacy of any and every truth claim, our ongoing appreciation for perceptible beauty in the world remains. (Just think of the last time you were truly arrested beyond words by the sight of a starlit sky, a vast mountain range, or a magnificent piece of artwork.) Such experience with a beauty beyond words serves as a theological defense against the suspicion that all rhetoric is inherently violent, or that “every discourse is reducible to a strategy of power.”10 Instead, beauty should remind us that not every
form of persuasion is inherently deceitful and self-serving; there is a form of rhetoric that is fundamentally grounded in an “ontology of peace.”

In short, with Balthasar, we should be able say that beauty does indeed confront and challenge us, sometimes radically so, to change our lives. On the other hand, with Hart, we are invited to appreciate that change as something ultimately performed within us by the very Source of beauty itself, calling us to a place of peace, even if, in many cases like Job’s, such peace awaits us only on the far side of much pain, confusion, and loss.

**JOB AND THE TRANSFORMATION OF THE SENSES**

Returning to the text of Job with all this in mind, it should be clear that of all the things Job suffers from, he surely does not suffer from our modern preoccupation with the boundary separating perceptual from conceptual knowledge. The anthropology woven throughout this Hebrew text is foreign to that of post-Cartesian Western philosophy. For Job, *to see is to know*. The concept embodies the percept, and vice versa, in ways that should provoke our attention.

Consider just a few comments drawn solely from Job’s thirteenth chapter, in his reply to Zophar the Naamathite. Speaking of the purported wisdom of his friends and the knowledge they think they offer, Job replies by first connecting his senses with their knowledge, and then explaining his need for knowledge of another order: “Look, my eye has seen all this, my ear has heard and understood it. What you know, I also know; I am not inferior to you. But I would speak to the Almighty, and I desire to argue my case with God” (Job 13:1-2). A bit later, he doubts if his companions’ words possess any real significance in comparison to a possible direct encounter with God, and he imagines what they themselves would do if given this latter opportunity: “Would not his splendor terrify you, and the dread of him fall upon you? Your maxims are proverbs of ashes; your defenses are defenses of clay” (Job 13:11-12).

Most importantly, though, notice Job’s clairvoyance about what his own, perceptual confrontation with God would mean to him, personally, regardless of the anticipated consequences: “Though he slay me, yet will I hope in him; I will surely defend my ways to his face” (Job 13:15). This demand for a face-to-face encounter is repeated six chapters later, and again, the crucial role of the senses is impossible to miss: “I know that my redeemer lives, and that at the last he will stand on the earth; and after my skin has been destroyed, then in my flesh I will see God; I myself will see him with my own eyes — I, and not another. How my heart yearns within me!” (Job 19:25-29).

As Providence would have it, Job does not have to wait for his skin to be destroyed. After many words have been shared and wisdoms pronounced by human tongues, the theophany of God comes to Job in the whirlwind. The most vibrant display of creation’s diversity is conjured by and through the living Word of the God now personally present to Job. Retrieving Steiner’s commentary about this “aesthetic” response from God in these sections (chs. 38-41), he writes:
Like some ultimate Leonardo, the Deity in *Job* promenades us through a gallery of masterpieces, of rough sketches, of enigmatically encoded patterns, of grotesques and anatomies. In sequences and cross-echoes whose delicacy and numbing power . . . have defied millennia of explication and hermeneutic analysis, God’s address to Job comes out of an artist’s workshop. Prize exhibits, opus numbers.

Indeed, only after the Master has brandished this *œuvre* is Job brought to profess his genuine humility, and his story of restoration begins: “Surely I spoke of things I did not understand, things too wonderful for me to know. ‘You said, ‘Listen now, and I will speak; I will question you, and you shall answer me.’ My ears had heard of you but now my eyes have seen you. Therefore, I despise myself and repent in dust and ashes” (Job 42:3-6).

By the time Job finally utters these words of *metanoia*, the Edomite has already been through a remarkable transformation. It clearly does involve the humiliation of his reason, yet Job’s constructive experience of “healing” has more to do with his perceptual encounter of the living God in his midst than it does with quieting his creaturely desire for knowledge, meaning, or purpose. The Creator interrogates his creature, but he does so through the diverse forms of creation as such, and thus Job is able to say: “My ears had heard of you . . . but now my eyes have seen you. Therefore, . . .” We can rightly surmise that Job’s actual, material circumstances have not changed at this point. The losses remain; the sores still weep. What has changed is Job himself, as an awesome and awful beauty has manifested before his very eyes. In the process, his entire person is transformed, including his senses; the world to Job looks different.

**JOB AND THE CLINIC TODAY**

In this final section, I will offer a few suggestions for what this biblical theology might mean in terms of contemporary medical responses to suffering. The first suggestion is, in fact, a word of caution. Nothing would more readily belie a posture of receptivity to transcendent beauty than to think we could rationally dissect Job’s experience, extract its component parts, and then re-package it all in the form of a prescriptive object of therapy, ready for use when needed. These lessons from Job hardly imply that health care providers should somehow take responsibility for inaugurating the same kind of transformation for sufferers today. At a more fundamental level, learning from Job at least means attending further to the dynamic range of our perceptual faculties. We are all capable of a profound participation, not just in this-worldly experiences of pain and suffering, but also in more-than-this-worldly forms of divine beauty, or simply put, grace.

Thus, as we connect this overall theology to the daily practices of medicine, we are obliged to attend more to the phenomenology of perception at work in our patients’ specific experiences in our various sites of healing. Such critical attention should serve as a consistent focus within clinical ethics as a field of research. For instance, there is already an abundance of empirical literature aimed at testing and evaluating the existential effects of verbal communication models between clinical staff and patients in a variety of cases.
and contexts, such as the disclosure of a cancer diagnosis in the exam room, and so forth. Yet when it comes to the aesthetic dimensions contextualizing all this interaction — by which I mean the particular images within one's field of vision, the various sounds in the background, the objects of touch, etc. — I think it fair to conclude that we still have not thought proactively enough about how this perceptual order conditions patient experience in dramatic ways.\textsuperscript{13}

This is unfortunate, for the sufferer is already struggling enough as it is, without also being besieged, if I may use the term, by careless aesthetics. Eric J. Cassell has written: “Suffering influences perception by changing the individual's total focus toward the source of suffering. The entire apparatus of perception, including the assignment of meaning, then contributes to the suffering. As this occurs, the person begins to adapt to the threat, and the nature of the person begins to change.”\textsuperscript{14} I hope to have made the case that we should at least have an expectation that beauty can often arrest and reverse such a debilitating transformation — but only if given the chance. Creating opportunities for such aesthetic encounters thus begins by giving more critical attention to the ways in which our contextual spaces are already influencing patient perception in certain ways, whether we mean them to or not.

To be sure, many facilities do exemplify the very finest degree of aesthetic coherence and intentionality, conscientiously incorporating what is being called “evidence-based design.”\textsuperscript{15} And when they do not, this is often the result of real-world limitations of budgeting, space, and resources constraining what we are able to accomplish. Nevertheless, beyond the dictates of necessity and function, many of our clinical spaces simply appear thoughtlessly designed and haphazard, not just by necessity and function, but again, by carelessness. One is often reminded of that classically-80s dystopian film by Terry Gilliam, Brazil, in which strange mechanical objects, oversized ventilation, obnoxious advertising and noisy gadgets are constantly preventing characters from performing the most basic of movements and conversations. Though conditions quite naturally reflect the ongoing integration of technology and medicine in today’s society, what gets lost in all this attention to the body is the patient's own perspective, especially of those liminal spaces in and between procedures and labs and so forth, moments that often impress the memory far more than we may realize. To be sure, the enculturation of medical professionals with the tools of their trade, or the resignation of overworked associates towards suboptimal conditions they feel disabled from changing, are understandable phenomena in themselves. Yet these factors still do not justify any lack of consideration on our part of the patient’s overall perception of our places of healing. The one who is suffering is already hypersensitized to every stimulus, vulnerable to every subtlety.

As I hope to have made plain, there is far more at stake in our facilities’ conversations about “aesthetics” than simply deciding what pictures look best on this or that wall in the waiting room. Yet, even when it comes to that particular topic of art and décor, there should surely be more of a shared, theological conversation underwriting such choices. It may bear reminding, for instance, that Matthias
Grunewald’s famous, but disturbingly grim, Isenheim altarpiece was originally hung in the hospital ward. While we may not wish to go to such lengths to “confront” our patients with this kind of beauty, it may not be entirely out of bounds to recommend putting a halt to the kitschy sentimentalism that pervades so many of our spaces. Such an aesthetic may in fact be preventing those in pain from engaging their plight in the way of Job, which is to say, pressing the Creator to somehow be made present on that supra-rational level described above. I was intrigued by a recent article dealing with this very question of “jolly art” in the hospital, in which it was argued that there is some neuroscientific evidence to support the idea that, instead of placid tableaus of soft landscapes being conducive to patient healing, hospital art should in fact be more arresting and provocative to viewers, inviting them to more actively and existentially engage its interpretation.16 This phenomenon could undoubtedly serve as part and parcel of patients’ holistic interaction with their respective conditions, as our specialists in art therapy already realize.

Finally, then, and on an individual level, those engaged in health care should be encouraged and empowered to practice a keener sensitivity to this other-than-sentimentalized kind of beauty, for the sake of their own formation and for the sake of their patients. Such a practice ought not be confused with simply greater exposure to or familiarity with art, though of course, that might be a help. Above all else, though, we are talking about cultivating what is essentially a spiritual discipline; a willingness to work at remaining open to the divine in our midst — in our surroundings and environment, yes, but also in and through the people who come to share spaces with us. Temptations to operationalize our vocations and close ourselves off to the happenings of the present are pervasive. It takes courage to “stay open.”

As a practical step in getting motivated in this direction, one of the best hours you could spend watching television, in my opinion, is an interview between Bill Moyers and Sr. Wendy Beckett. Sr. Wendy became somewhat famous for a series she hosted on the BBC about the history of art. In her interview with Moyers, though, Sr. Wendy roams broadly through a host of fascinating topics, and no doubt better communicates the substance of the “heady” theology I otherwise tried to present above, about our receptivity to beauty and what it means for our spirituality. When asked, for example, about what her personal practice of aesthetic contemplation has done for her, she replied that, while it has given her joy, it has also “increased my capacity to accept darkness and pain, and not be too bewildered by them.” She goes on:

> It has, I hope, made me a more sensitive and alert person. The one fatal thing is to be a zombie. And I think we’re all in danger of living part of our lives at zombie level. But I think art helps one to be perpetually there, as it were … because God’s coming every moment, but we’re not even noticing that He’s coming. We’re drifting through.17

In this way, beauty invites us day by day and moment by moment, to remain attentive and avoid “zombiedom,” lest we miss those
occasions in which an apparently ordinary conversation, procedure, test, or consult could become something deeply transformative.

**CONCLUSION**

This essay has sought to uncover how an appreciation of God’s “aesthetic response” to Job’s suffering exhorts all of us, especially those engaged in medicine, towards a more capacious interpretation of the patient’s process of healing through suffering, such that the patient’s spiritual senses are expected to be as active as the patient’s bodily senses. It was from a depth of pain and struggle in both body and spirit that Job found the boldness to demand a divine response to his condition, his questions, and his confusion. Like so many others in the grip of suffering, he longed to know what he had done to deserve it all: “I loathe my very life; therefore I will give free rein to my complaint and speak out in the bitterness of my soul. I say to God: Do not declare me guilty, but tell me what charges you have against me” (Job 10:1-2). The Scriptures disclose for us, however, a God who disregards such an invitation and prescribes instead a more radical form of therapy, subjecting Job to a transformational encounter that ultimately reorders his entire field of perception. Beyond the limits of reason, Divine Beauty persuades Job in the most holistic sense of the word, moving him from his prior relation to his suffering into a new relationship, not just to his suffering, but to the Creator himself.

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ENDNOTES

1 George Steiner, Grammars of Creation (New Haven: Yale University Press, 2001), 47.
2 Steiner, Grammars of Creation, 47-8.
5 Tham, “Communicating with Sufferers,” 86.
6 Tham, “Communicating with Sufferers,” 93.
7 Tham, “Communicating with Sufferers,” 89.
11 Hart, The Beauty of the Infinite, 3: “Christ is a persuasion, a form evoking desire, and the whole force of the gospel depends upon the assumption that this persuasion is also peace: that the desire awakened by the shape of Christ and his Church is one truly reborn as agape, rather than merely the way in which a lesser force succumbs to a greater, as an episode in the endless epic of power.”
12 Steiner, Grammars of Creation, 48.
16 Jonathan Jones, “Should hospital art be jolly – or should it portray the truth about pain? The Guardian, August 19, 2014, https://www.theguardian.com/artanddesign/jonathanjonesblog/2014/aug/19/hospital-art-jolly-pain-wellbeing-kitsch-grunewald. The author points to the research of Semir Zeki, a neurobiologist at University College London, who has done some intriguing work on the way our brains respond to visual stimuli.
17 “Sister Wendy in Conversation with Bill Moyers” (WGBH Educational Foundation, Boston, 1997), 46-47.
Legal Lens

THE PUBLIC CHARGE RULE’S IMPACT ON PUBLIC HEALTH
Towards the beginning of August, the Trump Administration expanded the decision-making process involved in granting green cards, also known as permanent legal status, to legal immigrants currently in the U.S. This expansion is based on a more aggressive wealth test of immigrants to determine whether they retain the means to support themselves, or whether they are likely to use government benefit programs such as food stamps, subsidized housing, and Medicaid. In essence, poorer immigrants that are deemed likely to require public assistance will be denied a green card, while wealthier immigrants, who are less likely to need assistance, will be granted a green card. This tool designed to narrow the demographic of immigrants permanently allowed in the U.S. is part of a new regulation called “The Public Charge Rule.” Financial status has long been a consideration of immigration officials, but this rule makes assessing finances a more essential part of the decision-making process. Officials have also claimed this rule will not apply to those already with green cards, certain members of the military, refugees and asylum-seekers, or to pregnant women and children, but this does not account for the confusion created among the immigrant communities. Immigrants may drop out of needed programs for fear that using them may impact their immigration status or the status of a relative. Examples of these programs include housing, forgoing critical lifesaving health care or preventative care, or refusing to seek supplemental nutrition such as the program for women, infants and children (WIC). The Department of Homeland Security estimated that more than 382,000 immigrants seek adjustment to their immigration status every year, making them subject to the Public Charge Rule. Further, when considering the 26 million immigrants living in the U.S. legally who may reconsider their use of public assistance, the public health implications may make for a humanitarian impact to be felt for decades.


HEALTH PLAN’S CADILLAC TAX MAY FINALLY BE RUNNING OUT OF GAS
The Cadillac Tax, a 40% tax on employer-provided health insurance plans that cost more than $11,200 for an individual policy and $30,150 for family coverage, is one of the most
controversial parts of the Affordable Care Act. Although the tax has been controversial since 2010, those supporting the ACA vouched that it was necessary to help pay for the cost of the law and prevent use towards care that could be deemed unnecessary. Now, the issue is not how much the nation is willing to spend on health care, rather it is the amount individuals actually are spending. Stan Dorn, a senior fellow at Families USA, stated, “Nowadays, few observers would argue that [employer-sponsored insurance] gives most workers and their families excessive coverage.” In his written statement, Dorn was advocating that although backers of the ACA thought the tax was necessary for those concerned about the price of health care, the increasing use of high-deductible plans, amongst other transitions, make the ACA backers’ argument less persuasive. Many economists from one ideological spectrum have supported its inclusion in the ACA, and many still endorse it. This contested debate amongst politicians over this issue will make it harder for a consensus on the issue to be formulated.

Julie Rovner, KHN, Aug. 16, 2019

NYC’S MEASLES OUTBREAK IS FINALLY OVER
The largest measles outbreak in the country in 27 years, representing a huge setback for public health, was officially declared over in New York City in early September. Although no new cases had been reported since mid-July, a measles outbreak is typically only declared over following two incubation periods. The efforts necessary to stop this highly contagious and potentially life-threatening disease cost the city over $6 million and required the deployment of more than 500 staff and the issuance of a mandatory vaccination order for people living or working in four neighborhoods of Brooklyn — where 72% of the cases occurred. The outbreak was mainly concentrated in the ultra-Orthodox Jewish community due to misinformation that spread about the safety and effectiveness of the measles, mumps and rubella (MMR) vaccine. The total infected were 654 people with 52 requiring hospitalization, 16 were placed in intensive care. Of those infected, 73% were unvaccinated, 7% were incompletely vaccinated, and 15% were unaware of their vaccination status. During the outbreak, New York lawmakers also limited the states vaccine exemption laws, revoking a parents’ ability to claim a religious exemption for mandatory school vaccinations. According to the New York Health Department, more than 26,000 children had previously gone unvaccinated for religious reasons in public and private schools and day-care centers across the state. Although transmission of measles may no longer be of heightened concern in New York City, it is important to remember the cost, monetary and otherwise, that these outbreaks force on communities, especially given other outbreaks in the U.S. and around the world.


MICHIGAN BECOMES FIRST STATE TO BAN FLAVORED E-CIGARETTES
Michigan Governor Gretchen Whitmer (D) ordered a ban on flavored e-cigarettes, stating that “My number one priority is keeping
our kids safe and protecting the health of the people of Michigan.” Whitmer also indicated that it is problematic that e-cigarette companies are using sweet flavors, such as bubble gum and “fruit loops”, to hook young people on these dangerous devices containing nicotine. The ban is supposed to last for six months, and shall be renewed for another six months. Meanwhile, the health department is supposed to develop more permanent restrictions banning the flavored e-cigarettes. Although Michigan is the first state to prohibit the sales of flavored e-cigarettes, in late June, San Francisco became the first city to ban the sale and distribution of all e-cigarettes. A proposal, urged by federal officials to the FDA last year, would bar the sale of sweet and kid-friendly vaping products in stores. This proposal is not yet finalized.

Laurie McGinley, The Washington Post, Sept. 3, 2019
https://www.washingtonpost.com/health/michigan-becomes-first-state-to-ban-flavored-e-cigarettes/2019/09/03/34f234c6-ce4c-11e9-8c1c-7c8ee785b855_story.html

COLLEGE GRAD BANNED FROM AMERICORPS POSITION FOR ANXIETY COUNSELING WINS REFORMS
AmeriCorps National Civilian Community Corps reached an agreement to revise its health screening process after an alleged violation of disability laws was announced by the American Civil Liberties Union. The ACLU filed an administrative complaint arguing that a national service program for young adults violated the Rehabilitation Act of 1973. This arose after the lead plaintiff, Susie Balcom, received an offer to work for the program. However, the offer was rescinded after Balcom disclosed in the medical questionnaire that she had attended three counseling sessions for anxiety. Resulting from this incident, AmeriCorps will implement a new health screening questionnaire, in addition to a new formal system in which reasonable accommodations can be requested.

Debra Cassens Weiss, ABA Journal, Sept. 18, 2019

UP IN SMOKE: VAPING TURNS DEADLY
Federal officials at the Centers for Disease Control and Prevention (CDC) have continued reports about the mysterious dangers and lung injuries related to vaping. As of mid-September, the number that have fallen sick has risen to 805 people across virtually all of the U.S., with 12 deaths being confirmed in 10 states. There are multiple factors inhibiting both the CDC’s investigation into the cause of the outbreak, and the criminal investigation being conducted by the U.S. Food and Drug Administration (FDA) and the Drug Enforcement Administration (DEA). The CDC explained that narrowing down the cause has been challenging because no single e-cigarette or vaping product, brand, or substance has been definitively linked to the outbreak. Also those currently hospitalized have used a wide variety of products with varying ingredients, and often they have reported a history of using both nicotine and THC products. There are also variances in where these products are acquired, some from stores, while others online or on the street. THC products purchased on the black market have come under increased scrutiny as investigations have expanded to
include possible manufacturers and distributors of these products. The suspected cause of these lung injuries is some kind of chemical exposure, with investigators currently focused on vitamin E oil, or vitamin E acetate. Vitamin E acetate has been used in the marijuana industry to “stretch out THC” used to fill vape cartridges since it is colorless, odorless, and much cheaper than THC oil. But health officials have warned of the health hazards related to inhaling vitamin E acetate, possibly creating a link between the symptoms reported by patients: “cough, shortness of breath, and chest pain.” These combined factors have made investigating the outbreak increasingly difficult, along with younger patients being more reluctant to share information as it relates to their use of marijuana.

Lena H. Sun, The Washington Post, Sept. 26, 2019

JOHNSON & JOHNSON MAKES A DEAL
To avoid trial, Johnson & Johnson (J&J) settled for $20.4 million with the two Ohio counties behind the opioid crisis lawsuit. The allegations against J&J stem from two of its opioid painkillers: the fentanyl patch, Duragesic, and a tapentadol pill, Nucynta. J&J is not alone in making a deal prior to trial; they are the fourth drug manufacturer to do so in the sea of lawsuits that municipalities and states have filed against similarly accused companies. J&J was accused of contributing to the widespread opioid-addiction crisis in two Ohio counties through aggressive marketing practices and lenient distribution policies. Their settlement includes a $10 million cash payment, a $5 million reimbursement for legal fees, and a $5.4 million charitable contribution to opioid-related nonprofits such as those treating babies born to opioid-addicted mothers. J&J claims this settlement allows them to avoid using resources in the uncertainties of trial and focus them towards making “meaningful progress in addressing the nation’s opioid crisis.” In this Ohio deal, J&J was not required to admit liability. They are facing other opioid lawsuits across the country. The bankruptcy of Purdue Pharma, maker of OxyContin, has cued J&J and other companies into possibly using bankruptcy in an attempt to reach a global resolution of these cases; progress into this argument will likely play out in the coming months.

https://www.wsj.com/articles/johnson-johnson-agrees-to-settle-ohio-opioid-lawsuits-for-20-4-million-11569977306

Physician and bioethicist Daniel Sulmasy argues that the rejection of physician claims of conscientious objection are often based on two premises that are rarely made explicit. The first is that the protection of religious liberty should be limited to freedom of worship, assembly, and belief. The second is that because professions are licensed by state, those who practice a licensed profession should be required to provide all the goods and services determined to fall within the scope of practice and permitted in that state, regardless of any personal philosophical, moral, or religious objection. In this paper, Sulmasy argues that these premises ought to be rejected.

The first premise is incompatible with Locke’s concept of tolerance, which recognizes that fundamental, self-identifying beliefs affect public as well as private acts and deserve a broad measure of tolerance. According to Locke, private worship and belief should be granted almost complete tolerance by the state, limited only by proscription of acts deemed against natural law or the good of the state. While the breadth of tolerance for conscientious objection in the public space should be narrower than tolerance for private belief and worship, this ability to refuse to provide certain tests or treatments based on one’s conscience is necessary for the flourishing of a truly pluralistic liberal democracy. Sulmasy addresses an important critique of this point by arguing that tolerance does not necessarily lead to moral relativism or subjectivism. Just because one firmly believes her convictions are true does not mean she is infallible, and she may confirm, without contradiction, that she could be mistaken in her views. Thus, as Sulmasy aptly notes, “epistemic moral humility” and “honest acknowledgment that one’s moral judgments are fallible” are the “true root[s] of tolerance” (p. 22).

The second premise, which claims that professionals licensed by the state should be required to perform any action that is legally permitted and under the scope of their practice, undermines the concept of professional judgment and shrinks what Edmund Pellegrino calls the “discretionary space” of the provider (p. 19). By examining the nature of a profession versus an occupation, Sulmasy poignantly argues that physician judgment is not only prudent but necessary to good medical care. He rightly claims that “professional licensure is permissive, not proscriptive” (p. 24) and highlights the importance to society of “cultivating physicians of conscience” (p. 25) who are able to make both technical and moral judgments in caring for their patients.
Sulmasy proposes, however, several Lockean limits to tolerance for physician claims of conscientious objection that would be “destructive of society.” First, we must ask, “does the act for which a claim of conscientious objection is made undermine or contradict the principle of tolerance itself?” (p. 27). Objections should only be respected if they refer to a class of actions, not to a class of persons. Second, Sulmasy asks, “does the act entail a substantial risk of serious illness, injury, or death for those who do not share the belief that is said to justify the practice?” (p. 28). If a patient faces imminent death, this might constitute grounds to compel conscience. However, such cases in medicine are rare, and a physician willing to perform the act in question can usually be found. Lastly, as a final limit to tolerance, we must ask, “is the act an action or a refraining from an action?” (p. 28). Generally, greater moral justification should be required to compel someone to perform an action than to compel someone to refrain from an action. Overall, Sulmasy’s careful and measured argumentation provides a convincing justification for the need to protect physician claims of conscientious objection in a pluralistic liberal democracy.


The literature arguing for and against health care professionals’ right to conscientiously refuse to perform certain medical procedures they personally consider immoral typically focuses on the perspective of physicians. Lamb and colleagues conducted a concept analysis of conscience and conscientious objection in the nursing literature in an effort to provide greater conceptual awareness and clarity for the nursing profession. By outlining definitions, key attributes, antecedents and consequences, and case studies, the authors successfully explore these concepts in a nursing context, which is important to advance the ethical practice of nursing.

One of the authors’ most insightful points is the distinction between moral distress and stress of conscience. While moral distress has been discussed extensively in the nursing literature and beyond, the authors note that there is significantly less discussion of the related but distinct concept of stress of conscience. Moral distress, in its original formulation, occurs when the nurse knows the right course of action to pursue but is hindered from doing so. Stress of conscience is a type of stress that can arise for nurses “when they repeatedly experience stressful situations that trouble their conscience” (p. 39). The main distinction between moral distress and stress of conscience is that the latter is concerned with “one’s core sense of fundamental morality,” or the faculty that helps them determine their moral actions (p. 40). Stress of conscience can lead to burnout, changing clinical areas, or even leaving the nursing profession (p. 43). Stress of conscience, however, should not be misconstrued with mere opinion. Rather, the beliefs and values each person holds are core to who they are and how they perceive themselves and others.

One way to address issues of conscience in nursing is through an appeal to conscientious objection. While conscientious objection is...
addressed in various nursing codes of ethics and federations across different countries, a wide range of guidelines still exists, causing confusion for nurses and nurse leaders and a hesitancy to make claims based on conscientious objection. Studies have found that nurses are hesitant to make conscientious objection claims due to fears of patient abandonment, stigma, or perceived inability to go against professional authority.

This study reveals that there are substantial gaps in the literature related to 1) the meaning of conscience for nurses, 2) the conceptual distinction between moral distress and related topics of conscience, and 3) the precursors and consequences of conscience in nursing care (p. 45). The authors conclude that more research is needed to explore the ways in which nurses’ conscience issues can be addressed in practice settings and to discover what contributes to or precipitates stress of conscience so that these experiences can be mitigated. The authors especially highlight the need for more studies on nurses’ experiences of using conscientious objection and the impact such objections have for their nursing practice. These studies could be particularly important to dispel some of the prejudice surrounding claims of conscience. This concept analysis thus offers an important step in expanding the conscientious objection discussion into the nursing profession, as well as supporting ethics-based nursing theory and evidence-based practice.


According to Bedford, opponents of institutional conscience typically appeal to an individualist anthropology and a privatized conscience. They claim that institutions cannot make conscientious objections because they are not autonomous individuals and thus do not have a conscience. Spencer Durland, one opponent of institutional conscience, claims that ascribing conscience to a hospital is nonsensical: “a hospital is not a person; it is a physical structure within which providers give medical care. It does not perform procedures or counsel patients. It does not take lunch hours or vacations. And it does not have a conscience” (p. 256). Thus, Durland’s argument follows that, because institutional conscience does not exist, Catholic hospitals should not receive conscientious protections. However, Bedford claims that this argument is based on a flawed understanding of the social nature of institutions and fails to consider the inherent relationality and dependency that characterize human institutions.

He first shows that institutions are characteristically human because they are “established to overcome human limitedness and dependence” (p. 26). Next, he argues that institutions are intrinsically social phenomena because 1) they produce goods that an individual is unable to produce on her own, and 2) they rely on social means, such as social agency and socially coordinated behavior, to pursue their institutional ends. Institutions rely
on the practical rationality of its members to apply institutional norms, manifested in values-content like policies or Ethical and Religious Directives for Catholic Health Care Services (ERDs), to particular situations. Institutional conscience is thus not something the institution has or possesses but rather “something that members do on the institution’s behalf” (p. 265).

Ultimately, Bedford defines institutional conscience as “a judgment of practical reason made by an individual on behalf of an institution, applying institutional norms to a particular situation” and directed toward institutional ends (p. 265). Through his careful explication of a social anthropology and an open, relational conscience, Bedford offers a compelling argument for the need to honor not only the institutional conscience of Catholic institutions but of all institutions. In our pluralistic society, Catholic institutions should not be barred from contributing to society and the common good simply because of the values and norms that guide their contributions (p. 265).

CONCLUDING OBSERVATIONS
These three articles explored the roles of conscience and conscience objection for the physician, the nurse, and the institution. While only Bedford explicitly examines the role of conscience in a Catholic health care setting, the conclusions drawn by both Sulmasy and Lamb et al. can certainly be applied to Catholic contexts as well. Furthermore, it is refreshing to see that authors are reflecting on the concept even outside of exclusively Catholic health care settings.

As new technologies continue to expand the range of what is medically possible, the church and those working in Catholic health care ethics will be forced to consider the limits of their personal and professional obligations, and these articles provide sound arguments for the need to respect claims of conscientious objection among physicians, nurses, and institutions.

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