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FEATURE ARTICLE

On Charlie Gard

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Eleven-month-old Charlie Gard was the subject of international news through much of the summer of 2017. In addition to receiving attention from Pope Francis, President Donald Trump, and Vice President Mike Pence, a number of Catholic ethicists weighed in—with some drawing different conclusions—on what, morally, ought to be done in this truly tragic case. In what follows, I provide a "moral note" that highlights some of these analyses and the questions they raised. I also offer some of my own commentary throughout this overview and in its conclusion.

The first question for ethics, as H. Richard Niebuhr famously taught, to be asked is, "What is going on?"[1] Hence, Lisa Fullam of the Jesuit School of Theology at Berkeley prefaced her thoughtful and nuanced article in *Commonweal*, "before the moral question can be addressed, the medical condition can use some explication."[2] And in an article for *America*, Michael Redinger, who is a psychiatrist and medical ethicist at the Western Michigan University Homer Stryker MD School of Medicine, similarly wrote, "In my profession it is often said that good medical facts precede good ethics."[3]

Charlie was diagnosed with encephalomyopathic mitochondrial DNA depletion syndrome (MDDS), with a mutation in his RRM2B gene. It is an extremely rare genetic condition for which there is no cure. As of 2013, fifteen infants have been diagnosed with RRM2B mutations. Severe multi-organ symptoms are the result, and those born with this condition die, as Fullam notes, "in early childhood at the latest." Charlie suffered persistent seizures, was deaf, had muscle weakness, and depended on a ventilator for breathing. He was in the neonatal intensive care unit at London's Great Ormond Street Hospital (GOSH). According to his attending physicians, Charlie had suffered from irreversible brain damage, keeping him on life support to assist his breathing only prolonged and increased his pain and suffering, and he was in the "terminal stages" of the disease. Therefore, they decided it was in Charlie's "best interest" that the ventilator should be withdrawn and that he should receive palliative care and be allowed to die.

His parents, Connie Yates and Chris Gard, upon finding out about a possible experimental treatment—a nucleoside therapy—appealed the hospital's decision and requested permission from a High Court judge to be allowed instead to remove him from the hospital in order to take him to New York City for that treatment. However, the High Court, and then the Court of Appeal and the Supreme Court, each agreed with the GOSH physicians' recommendation. The European Court of Human Rights judges were also unpersuaded to intervene by his parents. Still, he had another brain scan at GOSH to help determine whether he could receive experimental therapy.[4] Columbia University neurosurgery professor Michio Hirano, who flew to the UK hospital, studied the scan in order to determine whether Charlie could benefit from the treatment. Hirano had testified that there was approximately a 10 percent chance that Charlie would respond to this treatment. He had also been provided access to all of Charlie's records and was given an opportunity to examine him. Hirano, another international expert, and the GOSH team caring for Charlie met for several hours, to determine whether he should be permitted to travel to the U.S. for treatment. The judge from the High Court held further hearings in order to render another decision on July 27th, wherein Charlie was to be transferred to a hospice and have life support withdrawn. On July 18th the U.S. Congress granted Charlie permanent resident status in order for him to be flown to New York to undergo a therapy trial overseen by Hirano.[5] However, Charlie's parents came to the realization that his condition had deteriorated to the point that the experimental treatment had no reasonable chance of success. Charlie passed away on July 28th.

According to Fullam, "The central moral question in light of Catholic medical ethics is whether treatment offers hope of benefit that is proportionate to whatever suffering Charlie is capable of experiencing and would experience with further treatment." None of the Catholic moralists whose pieces I consider here disagreed about this being a pivotal question. The University of Dayton's Jana Bennett, who will part ways from Fullam regarding the answer, nevertheless similarly began her article in *America* with "the Catholic Church's distinction between ordinary means and extraordinary means of prolong life and seeking treatment," quoting St. John Paul II's words in *Evangelium Vitae*: "It needs to be determined whether the means of treatment available are objectively proportionate to the prospects for improvement. To forego extraordinary or disproportionate means is not the equivalent of suicide or euthanasia; it rather expresses acceptance of the human condition in the face of death" (no. 65).[6] So, while Catholic theological ethicists shared this as a moral framework for thinking through this case, they did differ on the conclusion to which it led them. Other moral questions, too, were raised in a number of these moralists' essays that are viewed as significant if not "central."

On the first question—about the traditional distinction between "ordinary" and "extraordinary"—Fullam noted that these "do not refer to the degree of novelty or technological complexity of a medical intervention." A ventilator, for example, can be either, depending on the patient's circumstances. She wrote, "Ordinary treatments hold the reasonable prospect of proportionate benefit and are morally indicated, while extraordinary treatments hold no such promise and may be discontinued." This distinction applies not only when deciding whether to forego a specific treatment, but also when deciding to discontinue one. Fullam added, "If continuing a medical treatment causes or prolongs suffering that is disproportionate to the benefit that the patient will likely gain from that treatment, then it is extraordinary" and may be discontinued.

Accordingly, Fullam referred to the medical team's reports that Charlie was "essentially nonresponsive, except to painful stimuli," and she observed that he was "not expected to recover the ability to breathe without a ventilator and will likely need tube-feeding permanently. His apparent reaction to painful stimuli makes it likely that medical interventions such as suctioning his airway would cause him pain. The nucleoside therapy has few side effects beyond the possibility of diarrhea. While his decline might be slowed by the projected treatment, the damage to his brain is permanent." Fullam thus concluded that "Charlie's existence seems to consist principally of experiencing pain, even if dimly." She added that, while most of us "are capable of interpreting pain and suffering in ways that can make it meaningful," Charlie's case was different in that he "cannot comprehend a greater good or reason for [his] pain, but can only experience it." In her view, Charlie's suffering was disproportionate to the unlikely benefits that nucleoside therapy might provide. Her answer to the question, then, was: "Continuing treatments that extend his pain without prospect of proportionate benefit also delay his entering into the next life, where mitochondria don't matter, and where every tear will be wiped away—and don't we all want what's best for Charlie?"

In a press statement, the Anscombe Bioethics Centre in Oxford concurred that this conclusion is "morally defensible."[7] In its view, "The statements that ventilation could itself be causing suffering and that it was producing only a poor 'quality of life' (i.e. state of health and well-being) together constitute an argument about whether this particular treatment is worthwhile." This mode of reasoning is "ethically defensible" from a Catholic standpoint, although argument may exist—as it has—about the conclusion.

Similarly, Redinger wrote that "the proper application of Catholic moral reasoning could be seen to ultimately support the…final decision to withdraw life support." In his view, the likelihood of any benefit from the experimental treatment was so "remote" that it would be "futile or, more accurately, 'nonbeneficial'…."

In the above considerations, a few ethicists also commented on two important theological points. As the statement from the Anscombe Bioethics Centre framed it, "There are two things that need to be kept in mind in end of life care: respecting life and accepting death." On the one hand, human life is to be respected, regardless of a person's age, mental ability, race, etc. As Bernadette Tobin, who is director of the Plunkett Centre for Ethics in Australia, observed, "Charlie's life has the same worth as does anyone else's life—that is what we mean by the *equality* of all human beings."[8] Yet, life is not an absolute good, to be preserved at all costs. Otherwise there wouldn't be martyrs. On the other hand, death is an evil to be avoided and resisted. Yet, from a Christian perspective anchored in belief in the resurrection of the dead, it is not an absolute evil, so at some point it may be accepted. With this in mind, a number of these ethicists expressed concerns about a "technocratic paradigm" that fuels vitalists' striving to use every means possible to preserve life. Though not accusing Charlie's parents of having "that mentality," London-based Catholic journalist Austen Ivereigh at *CRUX* wrote, "Because the means exist doesn't mean we should reach for them. We must discern—in this case, what is in the best interests of a vulnerable baby."[9]

A second question that some Catholic moralists asked was whether Charlie's attending team of health care professionals and the courts viewed his life, itself, as a "burden" that's not "worthwhile." As Tobin wrote, "What doctors have to evaluate is not Charlie's *life*, but medical *treatments* available to him." In other words, which medical treatment is in Charlie's best interests? Tobin was open to the possibility that "the burdens of a proposed treatment are likely [to] outweigh the benefits it promises," even though she was not convinced that this was the case. Fordham University's Charlie Camosy, in an article appearing at *CRUX*, believed that GOSH's "decision is a classic example of Pope Francis's now-famous image of 'the throwaway culture.'"[10] In Camosy's view, if Charlie "had the right kind of mental capacities," he wouldn't "be discarded" like GOSH and the courts had decided—moreover, Camosy averred "that the UK government is aiming at his death." If so, the intent in GOSH's withdrawing of the ventilator, he opined, "is, in fact, euthanasia," which is "an act or omission which by intention causes death." As a test of whether this is the case, Camosy added, "Suppose, for instance, that when Charlie is taken off of life support he actually continues to breathe on his own and refuses to die. Will those who made the decision be pleased with this outcome? Of course not."

For her part, Fullam took issue with those who alleged that the medical personnel involved in this case exhibited a "disregard for the human dignity of people with disabilities…." In her view, the staff at GOSH were not "life-denying monsters" but "professionals who have devoted their lives to the care of sick children." Again, she believed that "we all want what's best for Charlie" even though there's disagreement about what's "best." In another article at *CRUX*, Ivereigh wrote similarly about Charlie and his case:

> He elicited great love: Not just from his extraordinary parents whose testimony has moved the world, but from the hospital and the courts too, as well as public opinion. His case divided us because we cared enough to want to save him, or to want him to avoid unnecessary suffering.[11]

I would add that we should be careful about interpreting intent. In Ivereigh's view, Camosy's claim about the physicians' intent is "astonishing." I can imagine that the medical staff members who made the decision were not "pleased" one way or the other. If Charlie continued to breathe, I suspect they would have continued to provide care for him, perhaps with hope, but also probably with deep concern about minimizing his pain and suffering. I say this even as I share Camosy's concern about a "throwaway" mentality widespread today as evinced, for example, in the Netherlands. Still, as Ivereigh saw it, "The aim throughout this tragic case has never been the death of a child, but the defense of his best interests as a sick baby." And, according to David Albert Jones, who is the director of the Anscombe Bioethics Centre, in an article at the *National Catholic Register*, "Note that the issue was not about whether Charlie was a human being worthy of respect. The question was, rather, what treatments would be in Charlie's best interest, given his present condition and the likely benefits and burdens of treatment."[12]

Similarly, Bennett worried that the "focus of the court's documents is not on Charlie's imminent death, but on his brain function." If so, it would be a reflection of "our own societal failure to accept people with mental disabilities." She noted John Paul II's concern in *Evangelium Vitae* about prenatal diagnostic techniques that encourage selective abortion of babies who may have disabilities: "Such an attitude is shameful and utterly reprehensible, since it presumes to measure the value of a human life only within the parameters of 'normality' and physical well-being, thus opening the way to legitimizing infanticide and euthanasia as well" (no. 63). Bennett believed that the current understanding of brain health and mental well-being in Western society "is limited and involves more questions than answers." She urged Christians "to push against the subtle (and apparently well-meaning) bias perpetuated about disabilities," and she concluded that Christians should "support Charlie and his parents in their desire to seek further treatment."

So too did the Anscombe Centre express worry about the "opinions…also cited in court that seem to refer not to the worthwhileness of *treatment* but to the worthwhileness of Charlie's *life*." In its statement, the Centre conjectured that, charitably interpreted, "these are muddled ways of referring to the limited benefits of treatment relative to the burdens," but it added that it is possible that the other interpretation of such comments, like what we've seen above from Camosy and Bennett, may be onto something. That is, if those words truly "express a judgement that life with some disabilities is not worth living at all," then such a viewpoint "should be repudiated firmly."

A third question that Catholic moralists raised had to do with who decides what ought to be done for children in a case such as Charlie's. My colleague, the Orthodox Christian philosopher, bioethicist, and physician, Jeffrey P. Bishop, wrote: "The medical practitioners at Great Ormond Street Hospital have drawn a bright line on the floor, suggesting that they not only know what is good for Charlie, they know what is best for Charlie. He is 'better off dead' than alive in this condition. Whereas, for Charlie's parents, life can be good, even while on a ventilator, and even if Charlie may only achieve a minimal of sentience or awareness of their love."[13] What we have here, he observed, is a "contest of goods" that problematically arises in Western political and economic liberalism and "the illusion that somehow the state is capable of setting out laws, procedures, policies and institutions that are agnostic about the good, or the good life for individuals, and that the state is neutral when it comes to goods." Bishop rejected the bifurcation of facts and values that Camosy employed, and instead argued that medicine "is always already a moral endeavour and its knowledges and practices are always aimed at some notion of the good, even if only because the desire to heal - to do good - guides the kind of scientific questions that are asked." Nevertheless, Bishop seemed to side more with the parents: "What goods are possible in Charlie's case? Well, his parents think that his life is a good, even if there might be burdens for Charlie. If the experimental treatments work, and if they can treat his seizures, and if they can get him off the ventilator, he might be able to enjoy life. Each one of these facts have (sic) some possibility of success, and together could enable a myriad of other goods. Or perhaps they want to continue to show him love in just trying. After all, it is a good thing for parents to fight for their children in the face of what appears to them to be a grave injustice. Their way of being a family is a good way of being a family."

As for Fullam on this question, "Ordinarily, parents are the surrogates for their children, making medical decisions for them in light of the child's best interest." Tobin agreed that, "[g]enerally speaking, parents bear the often-onerous responsibility of making decisions about the welfare of their children and, in particular, of authorizing medical treatment." So, too, Camosy wrote that "Catholic moral theology generally lets those closest to the goods in question decide how to weigh them,… [and in] this case, those closest to the goods involved are obviously the parents." Of course, his qualifier "generally" is significant. Usually parents and medical practitioners agree; however, occasionally hospital staff may think that parents are wrong, as in this heart-rending case. As Tobin put it, "But if doctors think that parents are making a serious mistake, seeking either over-treatment or under-treatment, then they have a responsibility sensitively to try to convince the parents of that, and, if necessary, to involve a court." In the view of the Anscombe Centre, the UK courts may have "treated Charlie as if he had not parents or as if his parents had already been shown to be acting in a very unreasonable, albeit well-meaning way." The Centre's director, Jones, devoted more attention to this concern, and added, "Regrettably, the Court of Appeal did not consider the reasonableness of the parents' decision, but made its own independent assessment on the balance of the advantages and disadvantages of the medical steps under consideration," thereby treating "Charlie as if he had no parents and Charlie's parents as though they had no natural authority to speak for their own child."

In another article, appearing in *The Washington Post*, Camosy warned that physicians “regularly make profound mistakes,” noting that “the third-leading cause of death in the United States is medical error.”[14] Not only do they commit errors when making a diagnosis or a prognosis, physicians “rarely have serious training in ethics.” When rating the quality of life of their disabled patients, physicians give them lower marks than what the patients themselves do. Given all of this, Camosy held that the ones who are “qualified—indeed, entitled—to make decisions for a person such as Charlie” were the parents. Still, I would note that while this should be the presumption, it is also the case that parents make mistakes and often lack “serious training in ethics.”

As one of my teachers, Stanley Hauerwas, has asked in his important book, *Suffering Presence*, “Why do we think the family should have such high moral status or why should parents make the basic decisions concerning the care of their children?”[15] Hauerwas thinks such questions lack “rigorous investigation,” and he opines that what is important is not that the parents conceived the child, nor that they possess the material resources to raise it, but rather “whether they have the moral resources for such a task.”[16] And he is hesitant to assume that this is the case.

For Hauerwas, what is needed is a community of virtue, namely, the church, which consists of many parents and physicians and others, but which can train them (and us) to be, as the title of this particular book by him has it, a “suffering presence” for one another, especially those who are vulnerable and in need, including mentally disabled children and the dying. Ivereigh and others rightly highlighted Pope Francis’ (and Archbishop Peter Smith’s and the Pontifical Academy for Life’s) emphasis to Charlie’s parents that the church is “with them, praying for them, and insisting they had the right to care for him right up to the end.”[17]

In his *First Things* reflection following Charlie’s death, Camosy wrote, “Charlie does not belong to his physicians. He belongs to his parents. And they to him.” While true, in a way Charlie “belonged” to all of us, if such a word is even apt, for we are all called to be each other’s “keepers,” a “responsibility which every person has towards others,” as Saint John Paul II wrote in *Evangelium Vitae* (no. 8). Charlie’s baptism into the family that we call church committed us all to care for him, and it reminds us that he ultimately belongs to God. May Charlie Gard rest in peace.

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[1] H. Richard Niebuhr, *The Responsible Self: An Essay in Christian Moral Philosophy* (New York: Harper and Row, 1963), 60.

[2] Lisa Fullam, "Updated: The Best for Charlie, What the Catholic Moral Tradition Has to Say," *Commonweal* (July 12, 2017), https://www.commonwealmagazine.org/updated-best-charlie.

[3] Michael Redinger, "What Some Pro-lifers Have Overlooked in the Case of Charlie Gard," *America* (July 5, 2017): https://www.americamagazine.org/politics-society/2017/07/05/what-some-pro-lifers-have-overlooked-case-charlie-gard.

[4] https://www.thesun.co.uk/news/4041768/charlie-gard-latest-news-parents-talks-experts-great-ormond-street-hospital/

[5] http://www.telegraph.co.uk/news/2017/07/19/charlie-gard-granted-permanent-resident-status-us-can-get-medical/

[6] Jana Bennett, "Charlie Gard: A Story of Disability Bias," *America* (July 7, 2017): https://www.americamagazine.org/politics-society/2017/07/07/charlie-gard-story-disability-bias.

[7] http://www.bioethics.org.uk/images/user/charliegardstatement.pdf

[8] Bernadette Tobin, "The Fight over Charlie Gard: We Can Evaluate His Treatment, Not His Life," *ABC Religion and Ethics* (July 14, 2017): http://www.abc.net.au/religion/articles/2017/07/14/4702035.htm.

[9] Austen Ivereigh, "Doctors, Courts Not the Enemy in the Charlie Gard Case," *CRUX* (July 6, 2017): https://cruxnow.com/commentary/2017/07/06/doctors-courts-not-enemy-charlie-gard-case/.

[10] Charlie Camosy, "On the Charlie Gard Case, the Church Needs to be Clear and Prophetic," *CRUX* (July 3, 2017): https://cruxnow.com/commentary/2017/07/03/charlie-gard-case-church-needs-clear-prophetic/. Camosy makes the same points in Charles C. Camosy, "Learning from Charlie Gard," *First Things* (August 3, 2017): https://www.firstthings.com/web-exclusives/2017/08/learning-from-charlie-gard. In agreement with Camosy, see Michael Sean Winters, "Let Charlie Gard Live!" *National Catholic Reporter* (July 5, 2017): https://www.ncronline.org/blogs/distinctly-catholic/let-charlie-gard-live.

[11] Austen Ivereigh, "Is British or American view of Charlie Gard Tragedy More Catholic?" *CRUX* (July 25, 2017): https://cruxnow.com/commentary/2017/07/25/british-american-view-charlie-gard-tragedy-catholic/.

[12] David Albert Jones, "Who Guards the Gards?" *National Catholic Register* (July 11, 2017): http://www.ncregister.com/daily-news/who-guards-the-gards.

[13] Jeffrey P. Bishop, "Charlie Gard and the Goods of Medicine," *ABC Religion and Ethics* (July 17, 2017): http://www.abc.net.au/religion/articles/2017/07/17/4703291.htm.

[14] Charlie Camosy, "Who Gets to Decide if Charlie Gard's Life Is Worth Living? It Shouldn't Be His doctors," *The Washington Post* (July 13, 2017): https://www.washingtonpost.com/news/posteverything/wp/2017/07/13/who-gets-to-decide-if-charlie-gards-life-is-worth-living-it-shouldnt-be-his-doctors/?utm_term=.958ae0aa73bb. Camosy raises this concern again in his *First Things* piece,

"Learning from Charlie Gard." On this question, Wesley J. Smith goes to the extreme in claiming, "The refusal to allow Charlie's parents to remove their baby boy from the hospital is an act of bioethical aggression that will extend futile-care controversies, creating a duty to die at the time and place of doctors' choosing." Wesley J. Smith, "Whose Baby Is Charlie Gard, Anyway?" *First Things* (July 4, 2017): https://www.firstthings.com/web-exclusives/2017/07/whose-baby-is-charlie-gard-anyway.

[15] Stanley Hauerwas, *Suffering Presence: Theological Reflections on Medicine, the Mentally Handicapped, and the Church* (Notre Dame, IN: University of Notre Dame Press, 1986), 190.

[16] Ibid.

[17] Ivereigh, "Doctors, courts not the enemy in the Charlie Gard case." For the statement from the Vatican's Pontifical Academy for Life, see http://en.radiovaticana.va/news/2017/06/29/vaticans_academy_for_life_issues_statement_on_charlie_gard/1322138. A report on Pope Francis's tweet about Charlie Gard is available at https://cruxnow.com/vatican/2017/07/02/pope-francis-backs-parents-uks-charlie-gard-drama/. The statement by Archbishop Peter Smith is available at http://www.catholicnews.org.uk/Home/News/Charlie-Gard. Another brief overview of the Charlie Gard case is provided by Catherine Pepinster, "Charlie Gard Dies After Sparking a Global Debate on the Ethics of Life and Death," *Religion News Service* (July 28, 2017): http://religionnews.com/2017/07/28/charlie-gard-dies-after-sparking-a-global-debate-on-the-ethics-of-life-and-death/.

FEATURE ARTICLE

Assessing ROI for Clinical Ethics Consultation Services

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Core Competencies for Healthcare Ethics Consultation, 2nd edition from the American Society for Bioethics and Humanities poses a challenge to ethicists in the opening section on Evaluating Healthcare Ethics Services, "Healthcare ethics consultation services should be able to demonstrate their value to those who pay for the service, as well as to those whom the service is intended to serve."[1] A similar, yet somewhat more inflammatory challenge to the field was made nearly 25 years ago by Hoffman, "The fact that some legislatures and courts, and a powerful body like [*The Joint Commission*], appears to have wholeheartedly embraced these [ethics] committees is truly surprising given the paucity of data on their impact or effectiveness."[2] Our field has vigorously responded to this critique and we continue to develop tools and metrics to assess the *quality* of the services provided.[3] A more difficult task has been to determine how to measure the *value* of clinical ethics consultation services.[4]

This article will focus on three metrics that attempt to capture the value of a clinical ethics consultation service. Each of the three metrics will utilize quality data from the Premier Quality Advisor Database in order to establish deviations between observed and expected data to value the outcome. By using deviation between observed and expected, the methodology avoids some of the critiques appropriately levied against outcomes-based assessments as a proxy "to the demands of the medical marketplace."[5] Whether the outcomes-based assessment utilizes cost avoidance models,[6] reductions in length-of-stay,[7]or impact on treatment,[8] each methodology may implicitly suggest ethics consultation should be utilized to reduce costs, lengths-of-stay or to achieve particular clinical outcome.[9] In other words, deviation in observed versus expected avoids claims that clinical ethics consultation services should be operationally motivated to reduce cost or lower lengths of stay thereby creating "misalignment between outcomes-based assessment[s] and the intrinsic nature of clinical ethics consultation as a service."[10]

Methodology

Similar to a 2009 study in *Health Care Ethics USA*, [11] this study utilize the Microsoft Access database Ethics Tracker at Ascension Columbia St. Mary's in Milwaukee, Wisconsin. These data include clinical ethics consultations from 2009-2012.[12] Clinical ethics consultation services throughout that period were based on the definition provided by ASBH's *Core Competencies for Health Care Ethics Consultation* which could be characterized as a service model that uses an *ethics facilitation approach* framed by the mission, vision and values of the health ministry. These data include consultations requested by any member of the health care team with direct patient contact as well as those from the patient, family member(s) or surrogate decision-maker(s).

In addition to data captured from the Ethics Tracker database, aggregate quality data was accessed from the Premier QualityAdvisor database for the following fields:

LOS_{exp}	*Expected LOS* (length of stay) is the risk-adjusted patient LOS.
LOS_{obs}	*Observed LOS* is the actual amount of days attributed to the patient's in hospital stay.
$\text{Charges}_{\text{exp}}$	*Expected Charges* are the risk-adjusted charges associated with the LOS.
$\text{Charges}_{\text{obs}}$	*Observed Charges* are the actual charges related to the in hospital stay.
$\text{Readmission}_{\text{exp}}$	*Expected Readmissions* is the risk-adjusted readmission rate within 30 days of discharge from the index visit.
$\text{Readmission}_{\text{obs}}$	*Observed Readmissions* is the actual 30 day readmission rate of the defined cohort in the proposal

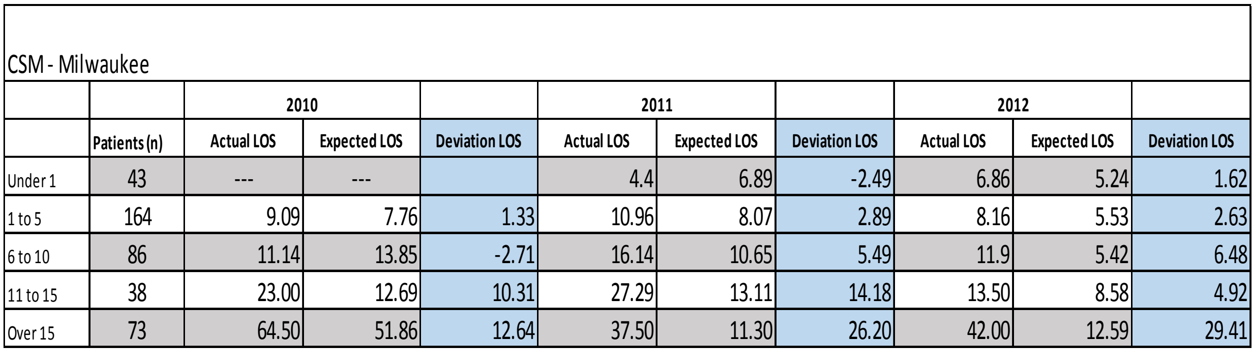
Each of these fields was used to compare observed versus expected for the outcome under analysis (e.g., LOS, charges, readmissions). Utilization of the Premier QualityAdvisor database on deviation of expected versus actual was found throughout Ascension's Clinical Excellence Programs which provided a statistically validated dataset for analysis.

Deviation, for the purposes of this study, is defined as the difference between the *actual value* and the *expected* (risk-adjusted) value for the outcome under analysis. A negative deviation (-) implies that the actual outcome was lower than predicted based on patient's characteristics when they were compared through Premier's risk adjustment methodology to similar patients in the comparative group. A positive deviation (+) implies that the actual outcome was higher than predicted based on the patient's characteristics when they were compared through Premier's risk adjustment methodology to similar patients in the comparative group. Deviation amount is expressed in the unit of measure for a particular outcome, for example, the deviation amount for LOS is days, charges are in dollars, etc.

Expected Versus Observed Length of Stay (LOS)

Method: Mean time from the patient's admission date to the date of ethics consultation date is counted in days and stratified in the following way: under 1, 1-5, 6-10, 11-15 and 15+. Cohort comparison analyses are based on the difference between LOS_{exp} and LOS_{obs} on all adult patients in the ICU from 2010 to 2012 to determine whether an early or late ethics consultation impacted the length of stay.

Table 1



CSM - Milwaukee

		2010			2011			2012		
	Patients (n)	Actual LOS	Expected LOS	Deviation LOS	Actual LOS	Expected LOS	Deviation LOS	Actual LOS	Expected LOS	Deviation LOS
Under 1	43	---	---		4.4	6.89	-2.49	6.86	5.24	1.62
1 to 5	164	9.09	7.76	1.33	10.96	8.07	2.89	8.16	5.53	2.63
6 to 10	86	11.14	13.85	-2.71	16.14	10.65	5.49	11.9	5.42	6.48
11 to 15	38	23.00	12.69	10.31	27.29	13.11	14.18	13.50	8.58	4.92
Over 15	73	64.50	51.86	12.64	37.50	11.30	26.20	42.00	12.59	29.41

Results*:* When ethics consultation is called within one day (mean time) of admission, LOS_{exp} versus LOS_{obs} deviations were highly favorable relative to ethics consultation. Although in 2010 these data were not available, in 2011 the LOS deviation for those who received an early ethics consultation were -2.49

days below the risk adjusted expected LOS. In 2012, the LOS deviation was only marginally greater at 1.62. Somewhat favorable results were also seen when ethics consultation was requested one to five days after admission. In 2010-2012 the deviation LOS was 1.33, 2.89 and 2.63 respectively (see Table 1). These data suggest that when ethics consultation is requested close to the patient's admission the patient's observed LOS will closely match the patient's risk-adjusted expected LOS.

Conversely, when ethics consultation is requested well after the patient's admission date—eleven to 15 days or over 15 days—LOS_{exp} versus LOS_{obs} deviations are significantly less favorable. For example, in 2010-2012, when ethics consultation was requested more than 15 days after the patient's admit date, the deviation LOS was 12.64, 26.20 and 29.41 respectively (see Table 1). These data suggest that when ethics consultation is appropriately utilized more than ten days after the patient has been admitted the patient's observed LOS will vary greatly from the patient's risk-adjusted expected LOS.

Expected Versus Observed Charges

Method: Similar to the previous analysis, mean time (in days) from the patient's admission date to the date of ethics consultation is stratified in the following way: under 1, 1-5, 6-10, 11-15 and 15+. Cohort comparison analyses are run on the difference between $\text{Charges}_{\text{exp}}$ and $\text{Charges}_{\text{obs}}$ for all adult patients in the ICU from 2010 to 2012 to determine the financial impact of early or late ethics consultation relative to admission date.

Table 2

CSM - Milwaukee										
		2010			2011			2012		
	Patients (n)	Actual Charges	Expected Charges	Charges Deviation	Actual Charges	Expected Charges	Charges Deviation	Actual Charges	Expected Charges	Charges Deviation
Under 1	43	---	---		$41,104	$39,016	$2,088	$ 44,023	$ 38,936	$ 5,087
1 to 5	164	$ 61,819.36	$ 50,802.73	$ 11,016.63	$ 75,618.05	$ 54,960.13	$ 20,657.87	$ 53,277.00	$ 39,297.52	$ 13,979.48
6 to 10	86	$ 95,289.43	$ 94,556.57	$ 732.86	$ 128,445.07	$ 100,460.00	$ 27,985.07	$ 105,355.40	$ 43,843.00	$ 61,512.40
11 to 15	38	$ 196,994.00	$ 57,380.00	$ 149,614.00	$ 254,109.88	$ 115,834.25	$ 138,275.63	$ 177,194.50	$ 118,840.00	$ 58,354.50
Over 15	73	$ 369,908.00	$ 262,758.50	$ 107,149.50	$ 331,939.09	$ 81,149.18	$ 250,789.82	$ 427,786.50	$ 121,711.63	$ 306,074.87

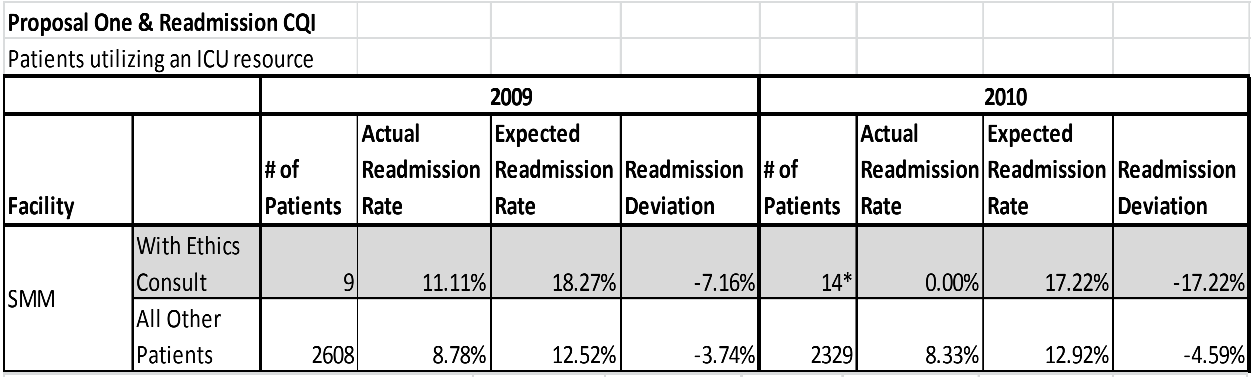
Results*:* When ethics consultation is called close to admission (within one day mean time of admission) Charges$_{exp}$ versus Charges$_{obs}$ deviations were favorable relative to ethics consultation. Although again in 2010 these data were not available, in 2011 the charges deviation for those who received ethics consultation was only slightly above the expected charges at $2,088. In 2012, the charges deviation was only marginally greater at $5,087. Unlike the deviations in LOS that trended significantly upward when ethics consultation occurred further from the patient's date of admission, charges deviations increased when ethics consultation was delayed by more than a day after the patient's admission. These data suggest that when ethics consultation is appropriately utilized close to the patient's admission the patient's observed charges will closely match the patient's risk-adjusted expected charges.

Conversely, when ethics consultation is delayed even for a brief time after the patient's admission date, Charges$_{exp}$ versus Charges$_{obs}$ deviations are significantly less favorable. The most striking example occurred in 2010-2012. When ethics consultation was requested more than 15 days after the patient's admit date, the charges deviation was $107,149.50, $250,789.20 and $306,074.87 respectively (see Table 2). This suggests that when ethics consultation is appropriately utilized too far after admission, the patient's observed charges will likely vary greatly from the patient's risk-adjusted expected charges.

Expected Versus Observed Readmissions

Method: We calculated the readmissions deviation between Readmission$_{exp}$ and Readmission$_{obs}$ for those ICU patients who received ethics consultation and for those ICU patients who did not receive ethics consultation from 2010-2012. For the purposes of this final method, only ethics consultations in the adult ICU met inclusion criteria.

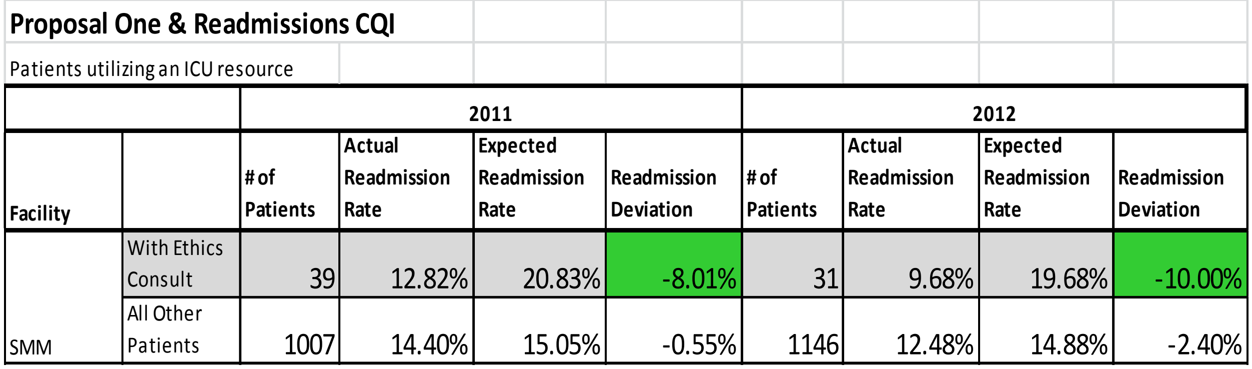
Table 3



Proposal One & Readmission CQI

Patients utilizing an ICU resource

		2009				2010			
Facility		# of Patients	Actual Readmission Rate	Expected Readmission Rate	Readmission Deviation	# of Patients	Actual Readmission Rate	Expected Readmission Rate	Readmission Deviation
SMM	With Ethics Consult	9	11.11%	18.27%	-7.16%	14*	0.00%	17.22%	-17.22%
	All Other Patients	2608	8.78%	12.52%	-3.74%	2329	8.33%	12.92%	-4.59%



Proposal One & Readmissions CQI

Patients utilizing an ICU resource

		2011				2012			
Facility		# of Patients	Actual Readmission Rate	Expected Readmission Rate	Readmission Deviation	# of Patients	Actual Readmission Rate	Expected Readmission Rate	Readmission Deviation
SMM	With Ethics Consult	39	12.82%	20.83%	-8.01%	31	9.68%	19.68%	-10.00%
	All Other Patients	1007	14.40%	15.05%	-0.55%	1146	12.48%	14.88%	-2.40%

Results: In all years, 2009-2012, readmission deviations were favorable to the risk-adjusted readmission$_{obs}$ for ICU patients who received ethics consultation. Most notably, readmission deviation in 2011 and 2012 represented a large enough cohort to reach statistical significance ($p < 0.001$ in green).

If we compare readmission deviation rates for adult ICU patients who received ethics consultation to all other adult ICU patients, the cohort positive for ethics consultation was favorable in all years 2009-2012. Impact on decreasing ICU readmission rates among patients who received ethics consultation continued from 2009 through 2012 even as the number of patients receiving ethics consultation increased. Finally, of note is the readmission$_{obs}$ rate for 2010 which came in at 0.00% for the adult ICU patient population who received ethics consultation.

One limitation on this particular method is the inclusion of mortality in the readmission deviations rate. Although death is typically seen as a reviewable event from a continuous quality improvement standpoint, ethics consultation in which the patient's hospitalization resulted in death is not necessarily inconsistent with quality. For example, a consultation may recommend withholding resuscitation for a patient with profound comorbidities when the clinical team does not find the medical intervention of resuscitation of physiologic benefit to the patient. The patient's death does not mean the ethical consultation lacked quality.

Another limitation in this method is the relatively small number of patients in the "with ethics consultation"' cohort for 2009 and 2010. Although in 2011 and 2012 the same cohort did reach statistical significance, the field would certainly benefit from larger studies to determine whether these results are unique to the Ascension Columbia St. Mary's Milwaukee location.

Conclusion

Determining the value of clinical ethics consultations remains a challenge for the field. In addition, it is important in light of this challenge that we not use value as a synonym for quality. Quality in ethics consultation continues to focus on evaluation standards of structure, process and outcome.[13] Assessments of structure and process are clearly important to an overall assessment of quality, but a high quality structure and process does not necessarily suggest the service is of value, [14] and value is really what is at issue here. Outcome measures face additional critiques for at least two reasons: (a) outcomes are contingent on the nature of the consultation and (b) are often outside the control of the person providing ethics consultation.[15] Value, on the other hand, is the demonstration of the contribution the service makes to the overall good of the patient. For Catholic health care that claim is circumscribed by our obligation to our identity and mission.

The proposed methodology offers three metrics to demonstrate the value of clinical ethics consultation relative to the overall good of health care delivery for the patient. These metrics are an attempt to contribute to the discussion of value without being subject to the critiques noted above. This methodology allows clinical ethics consultation to demonstrate its impact on established quality metrics rather than attempt to value the service through satisfaction assessments of either the user or recipient of ethics consultation. At the very least, this study attempts to value clinical ethics consultation services in a way that does not fall prey to an outcomes-based approach that may subvert or undermine the very nature of the service provided.

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[1] American Society for Bioethics and Humanities (ASBH). *Core Competencies for Healthcare Ethics Consultation, 2nd edition.* (Chicago, IL: ASBH) 2011, 34.

[2] DE Hoffman. "Evaluating Ethics Committees: A View from the Outside." *The Milbank Quarterly,* v.71, no.4 (2011): 677-701

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[6] BJ Heilicser, et al. "The Effect of Clinical Medical Ethics Consultation on Healthcare Costs" *The Journal of Clinical Ethics* v. 11, no. 1 (2000): 31-38.

[7] LJ Schneiderman, et al, "Impact of Ethics Consultation in the Intensive Care Setting: A Randomized Controlled Trial." *Critical Care Medicine* v. 28, no. 12 (2000): 3920-3924; MD Dowdy, et al. "A Study of Proactive Ethics Consultation for Critically and Terminally Ill Patients Extended Lengths of Stay." *Critical Care Medicine* v. 26, no. 2 (1998): 252-259

[8] LJ Schneiderman, et al, "Effect of Ethics Consultations on Non-beneficial Life-Sustaining Treatments in the Intensive Care Setting: A Randomized Controlled Trial." *JAMA* v. 290, no. 9 (2003): 1166-1172.

[9] Batten, 149; Heilicser, et al, 27.

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[10] Batten, 146.

[11] M Repenshek. "An Empirically-Driven Ethics Consultation Service." *HCEUSA* v. 17, no. 1 (2009): 6-17.

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[13] ASBH, 34.

[14] Pearlman, 4.

[15] Batten, 147-148.

Dealing with Racist Patient Requests: Law, Rights and Catholic Identity

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Background

Recently our ethics committee was approached with a request from the medical executive committee at one of our hospitals. An incident had occurred where a patient had been admitted through the emergency department and assigned to the hospitalist service. The hospitalist assigned to that unit, who is African American, attended to the patient. Later, the patient requested another physician be assigned to his care due to the physician's race. The request was not made to the physician but to the patient's nurse who then communicated with the African-American physician who in turn spoke with the head of hospitalist program as to how to proceed.

The head of the hospitalist program consulted the vice president for medical affairs who then conferred with the hospital's compliance officer who advised that the patient's preferences should be honored and another hospitalist assigned to the case. Briefly, the compliance officer's rationale was that we typically grant patients wide latitude in choosing their physicians and CMS regulations are clear regarding patients' right to choose their providers. Additionally, he argued that rejection of the patient's request might place the physician in a hostile work environment and subject her to additional distress. Accordingly the patient was assigned a different physician. The clinical course was unremarkable, but the physician who had been reassigned and her colleagues in the hospitalist program were dismayed that the institution had complied with a racially-motivated request. This seemed to them contrary to our Catholic identity and espoused mission and values. They brought the matter to the medical executive committee. They asked the ethics committee for guidance and policy development.

This incident was not unique. In my career I've encountered several similar patient requests, although they involved nursing and other allied health professionals. With the growth in employed physicians, hospital medicine, and patients routinely being attended by other than their personal physician, the incidence has undoubtedly spread to physicians. Fordham University Law Professor Kimini Paul-Emile writes that "one of medicine's open secrets is that patients routinely refuse or demand medical treatment based on the assigned physician's racial identity, and hospitals typically yield to patients' racial preferences." [1]

The reasons offered by hospitals both anecdotally and in court proceedings typically mirror the initial reasoning by the compliance officer in this case. Institutions typically acquiesce to racially motivated staffing demands in order to prioritize the patient's needs above the caregiver and thus enhance the therapeutic milieu, patient satisfaction and to avoid stressful or hostile work environments.

Numerous accounts of these requests and the moral distress felt by physicians and other caregivers are found in both scholarly and popular literature.[2] In a 2013 essay, Dr. Sachan Jain described an encounter with a racist patient and his angry response.[3] The responses from fellow physicians, by way of letters to the editor, demonstrate a clear lack of consensus as to the appropriate professional and institutional response.[4]

How should Catholic institutions respond to these requests? Guidance can be found in the intersection of employment law, patient rights, secular bioethics, and careful moral deliberation in light of our Catholic identity and witness.

Legal and Regulatory Guidance

A review of the pertinent legal and regulatory environment is unanimous that reassigning **employees** to comply with racially-motivated requests violates employment law. The Civil Rights Act (CRA) of 1964 was landmark legislation aimed at eliminating racial discrimination. Title VII of the CRA speaks to employment law and is applicable to our analysis. Title VII bars racial discrimination by employers based on race, color, sex or national origin. It further defines that "it shall be an unlawful employment practice for an employer to limit, segregate, or classify his employees or applicants for employment in any way which would deprive or tend to deprive any individual of employment opportunities or otherwise adversely affect his status as an employee, because of such individual's race, color, religion, sex, or national origin."[5] The Equal Opportunity Employment Commission (EEOC) enforces Title VII and cites several cases where hospitals, nursing homes and home health agencies violated Title VII by reassigning staff based on patient/client preferences. These cases include nurses who were barred from caring for a white newborn baby due to the racial preferences of the baby's father, certified nursing assistants (CNAs) who were assigned by a home health agency based on client racial preferences and nursing supervisors who were reassigned based on a patient's racially motivated request.[6] Although these cases involved licensed and unlicensed nursing personnel, I believe they would apply equally to employed physicians and other employed caregivers. There are no recorded instances of physicians filing EEOC complaints or lawsuits but this may stem from their previous non-employee status and/or a professional ethos that addresses questions of reassignment among peer physicians and not through the employer relationship. As Paul-Emile notes in his extensive UCLA law review article "the decision to accede to patients' requests for same-race physicians is not made by hospital administrators but rather by physicians who are deciding among themselves how best to meet each patient's needs."[7] This may be true in some cases, but in the situation I have described, employed physicians were seeking guidance from hospital administration.

Patient Rights and Medical Ethics

The legal landscape is fairly clear regarding these cases but we need to look beyond a naive legal positivism to examine other concerns. Patient rights, informed consent, capacity judgments, additional regulatory concerns, e.g. Emergency Medical

Treatment & Labor Act, the church's teaching on justice and human dignity, and the professional obligations of physicians, all play a role in an adequate examination of these requests.

A competent patient has the right to refuse medical treatment. This right is grounded in constitutional liberty interests and the doctrine of informed consent. It seems self-evident that this right would extend to refusing treatment from a particular provider, and the AMA code of ethics supports patient choice in selecting a physician.[8] Outside of the hospital setting a patient can routinely choose a physician based on any number of reasons that may be *prima facie* discriminatory. In the most benign example, it is uncontroversial that a patient may choose a physician based on gender due to the sensitive nature of the physical examination. Similarly a patient may choose their personal physician based on racial concordance, age, country of origin, religion or any number of qualifications which might be considered inappropriate and illegal from an employer perspective.

Currently when a patient is hospitalized or treated in an emergency room they are unable to exercise these preferences. With the advent of hospitalist medicine, patients are typically attended by physicians not of their own choosing. Assuming the hospitalized patient is either seriously ill or being evaluated for serious illness, it seems that our ethical obligations are not exhausted by simply refusing to comply with a racially-motivated request if such action on the part of the professional or institution might lead to a further deterioration of the patient's condition or even disability or death.

In a thoughtful 2016 article, K. Paul-Emile and his colleagues consider five practical and ethical considerations in evaluating racially-motivated patient refusals: "the patient's medical condition, his or her decision-making capacity, options for responding to the request, reasons for the request, and effect on the physician."[9] The authors argue that each case must be evaluated on its particular circumstances. They present several scenarios that might call for accommodation on the part of the professional and institution, e.g., a patient with diminished mental capacity might make a racially motivated treatment refusal but we would not hold that patient morally responsible due to their diminished cognition; a minority patient might request a racially concordant physician due to “a history of discrimination or negative experiences with the healthcare system” or “a veteran with post-traumatic stress disorder who refuses treatment from a clinician of the same ethnic background as former enemy combatants.”[10] They contrast these examples with rejections that are motivated by bigotry and argue that these bigoted rejections “are less deserving of accommodation.”[11]

Each of these examples differs in significant ways and the justification for each accommodation would rest on different conceptual and empirical grounds.[12] In urgent circumstances a physician might need to treat a hostile patient even in the face of antagonistic and racist behavior.   In balancing employment interests with the obligations of the doctor *qua* physician the authors tilt towards professional obligations arguing that physicians in these cases “should also subordinate their self-interest to a patient’s best interests and overcome any aversions they may have toward patients.”[13]

Without closely examining each of these examples it seems reasonable to acknowledge that some racially motivated requests may be deserving of accommodation based on prudent clinical judgment and principles of medical ethics and medical professionalism. The authors also provide a helpful decision matrix for clinicians and hospital officials to utilize in evaluating requests for reassignment.

Legal and regulatory guidance instruct us that racially motivated reassignments should probably not be permitted. In broadening our scope to include patient rights and preferences and the ethical obligations of physicians we acknowledge that some accommodations may be appropriate. How would these considerations play out in light of our Catholic identity and traditional moral analysis?

Catholic Identity and Racism

Our Catholic tradition makes clear that racism is unacceptable and a sin. *The Catechism of the Catholic Church* declares: “Every form of social or cultural discrimination in fundamental personal rights on the grounds of sex, race, color, social conditions, language, or religion must be curbed and eradicated as incompatible with God's design."[14] In 1979, the U.S. bishops spoke powerfully that "racism is a sin: a sin that divides the human family, blots out the image of God among specific members of that family, and violates the fundamental human dignity of those called to be children of the same Father. Racism is the sin that says some human beings are inherently superior and others essentially inferior because of races."[15] This pastoral letter went on to call on Catholic institutions "such as schools, universities, social service agencies, and hospitals, where members of racial minorities are often employed in large numbers, review their policies to see that they faithfully conform to the Church's teaching on justice for workers and respect for their rights."[16]

The church and Catholic health care as a ministry of the church are challenged to denounce racism and defend victims of racism. As we read in the *Ethical and Religious Directives*, "Catholic healthcare should distinguish itself by service to and advocacy for those people whose social condition puts them at the margins of our society and makes them particularly vulnerable to discrimination."[17] This obligation certainly should begin with our fellow co-workers in the ministry who are victims of discrimination within our very walls whether they are physicians, nurses or other staff. Returning to our original case, we hear in the voices of the physician who was rejected and her colleagues the voice of prophecy and solidarity asking the ministry to be faithful to its identity.

As our ethics committee pondered policy implications we agreed with the authors of the NEJM article that not every racially motivated refusal or request is racist. If an African-American patient requests a racially concordant physician because of positive experiences with concordant physicians he would not be denying the human dignity of a white physician. This would not be a racist act. However, we believed these cases were the exceptions, i.e., most cases of providers being rejected based on race are indeed racist acts. Is complying with such a racist request furthering the evil of racism? The principle of cooperation can guide us.

Christian discipleship requires us to be in the world, a world of much good as well as a world of sin and evil. Catholic health care serves people and people will sin. Even our Holy Father, Pope Francis, introduced himself by saying, "I am a sinner."[18] Many patients, including those guilty of crimes, engage in morally objectionable behavior that does not limit their right to receive care. We are called to serve sinners but not to cooperate in sinfulness. The ERDs speak to this in Part I of the Directives in reference to not offering morally wrong medical procedures.[19] We could extend that principle to other evil acts like racism.

How would the principle of cooperation apply to a racist request[20] for reassignment by a patient? If the patient simply refused care based on a racist proposition and left the facility there would be no cooperation, but if the facility acquiesced to the request there could be cooperation in the evil act. Clearly it would not be formal cooperation. There would be no intention on the part of the physician or hospital to participate in the racist act, but rather a desire to serve an ill person who is acting in a morally objectionable manner. Compliance would be material cooperation. Material cooperation is only licit when certain conditions are met. As Germain Grisez, (following St. Alphonsus Ligouri) outlined in his magnum opus *The Way of the Lord Jesus,* "The first condition for the moral acceptability of material cooperation is that the cooperator's act be "good or indifferent in itself"—that it not be evil independently of its constituting cooperation. The second condition is that the cooperator have in view as his or her end a reason that is "just"—that is, have a reason that is morally acceptable in itself. The third condition is that the morally acceptable end in view that is the cooperator's reason for acting be proportioned to two things: the gravity of the wrongdoing to which his or her action contributes and the proximity of that contribution to the wrongful deed—in other words, how closely the cooperator's outward behavior involves him or her in the outward behavior that carries out the wrongdoer's bad choice."[21]

In our case the first two conditions appear to be met. Assigning someone to provide care to a seriously ill person is a morally good act and the intent of the hospital is "just;" its intent is to prevent a deterioration in the patient's condition. As to the third condition it would depend on the circumstances of the case: Is the request truly racist, how recalcitrant the patient is in his demands, the seriousness of the patient's illness, their capacity to make decisions, the distress felt by the rejected caregiver, the ability of the patient to transfer to another facility for care, etc. We take seriously Grisez’s admonitions that material cooperation “can have bad moral effects on the wrongdoer, scandalize third parties, lead to disharmony between the cooperator and the victims of the wrongdoing, impede the cooperator from offering credible witness against the wrongdoing, and/or impede the cooperator from carrying out his or her vocation in other respects.”[22] Indeed we experienced some of these effects in the responses of the physicians who were involved in these cases. Taking this analysis into account we decided that in our policy the default position would be that refusals based on racial characteristics would be honored as treatment refusals but that the hospital would not reassign staff in order to assist in a racist refusal. We believe that such requests for reassignment must be rejected in light of our Catholic identity and the requirements of Christian witness. Patients who make such requests will be informed of our policy and counseled to accept care in a respectful manner from the treating physician. Rude, hostile or otherwise unacceptable behavior will be addressed according to current policy. Patients who are stable will be offered the opportunity to transfer to another facility. In those cases where a patient continues to refuse treatment, and in the clinical judgment of the medical staff a serious deterioration of the patient’s condition might result, we believe the requirements for licit material cooperation would be met and the reassignment could occur when all other efforts fail. This policy was presented to the medical executive committee and there was concurrence that this was an appropriate position both medically and ethically.

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[1] Paul-Emile, K., et al. “Patients’ Racial Preferences and the Medical Culture of Accommodation,” *UCLA Law Review.* 462 (2012)

[2] Chen. P., “When the Patient is Racist,” *The New York Times.* July 25, 2013

[3] Jain. S., “The Racist Patient,” *Annals of Internal Medicine* 2013: 158:632.

[4] Galishoff, M. et al. “Comments and Responses. The Racist Patient.” *Annals of Internal Medicine*,159:227-228

[5] The Civil Rights Act. Title VII. SEC. 2000e-2. *[Section 703]. Online:* https://www.eeoc.gov/laws/statutes/titlevii.cfm

[6] The Equal Employment Opportunity Commission. Significant EEOC Race/Color Cases. Online:

https://www.eeoc.gov/eeoc/initiatives/e-race/caselist.cfm

[7] Paul-Emile,K. “Patients’ Racial Preferences and the Medical Culture of Accommodation,” *UCLA Law Review* 462 (2012) p.484

[8] American Medical Association. *AMA Principles of Medical Ethics.*Chicago, IL: American Medical Association; 2001. Online: https://www.ama-assn.org/delivering-care/ama-code-medical-ethics

[9] Paul-Emile, K., Smith, A., Lo, B., and Fernandez A. “Dealing with Racist Patients.” *NEJM*. 374:8 p. 709.

[10] Ibid. p. 710

[11] Ibid. P. 710. See also Kyle Anstey and Linda Wright, Responding to Discriminatory Requests for a Different Healthcare Provider” *Nursing Ethics* 2014 (21:1) 86-96, for a careful analysis of cases similar to this and an algorithmic chart that plots different outcomes.

[12] Cooper, LA, Roter, DL, Johnson, RL, Ford, DE, Steinwachs, DM, Powe, NR. “Patient-centered communication, ratings of care, and concordance of patient and physician race.” *Annals of Internal Medicine* 2003;139

[13] Paul-Emile, K. et al. “Dealing with Racist Patients,” NEJM. 374:8 p. 710.

[14] *Catechism of the Catholic Church,* 1997 #1935 Online: http://www.vatican.va/archive/ccc_css/archive/catechism/p3s1c2a3.htm

[15] USCCB, “Pastoral Letter on Racism: Brothers and Sisters Among US,” 1979.online: http://www.usccb.org/issues-and-action/cultural-diversity/african-american/brothers-and-sisters-to-us.cfm

[16] Ibid.

[17] *Ethical and Religious Directives for Catholic Health Care Services*. Fifth Edition. 2009 p.8.

[18] Bullivant, S. “‘I Am a Sinner’: The Deep Humility of Pope Francis.” *America.* September 25, 2013

[19] *Ethical and Religious Directives for Catholic Health Care Services.* Fifth Edition. 2009 p.8.

[20] See Anstey and Wright who believe it is important to determine if the request is indeed racist, or if it is the result of cultural or religious factors, or past negative or traumatic experiences (93).

[21] Grisez. G., *The Way of the Lord Jesus*. Appendix 2. Online: http://www.twotlj.org/G-3-A-2.html

[22] Ibid.

Ethics and Antimicrobial Resistance

Anti-microbial resistance could turn out to be the biggest health crisis of our lifetimes. Few of us even remember pre-antibiotic days, when people routinely died of TB, pneumonia and even STDs. Plus, our experience of modern health care has been one of steady progress. New and better therapies and procedures are developed constantly, and those we have get better, cheaper and more readily accessible. Loss of antibiotics would be an unprecedented step backwards. Not only would our ability to fight infection not improve, it would return to levels that in the past allowed catastrophic health crises such as the Black Plague.[1] Medical problems like Lyme disease and MRSA could become crises overnight.

There are several aspects to the ethical questions that surround antimicrobial resistance. The most obvious is the threat that it poses to present populations. Lack of effective treatment for infectious disease is something like pollution – it affects everyone. Pandemics are a very direct threat to the common good. They affect not only health, but education, employment, and even defense. So it seems government has a duty to do what it can to prevent such outbreaks.

Another issue is stewardship. How did we get to the point of such widespread anti-microbial resistance? How did it happen that this incredibly valuable resource was overused – often not even on humans, but on livestock to prevent disease and accelerate the move to market?

Who has authority to allocate and control the use of such resources? The market? National governments? A global agency such as WHO or the UN? There are important efforts to address the issue by government and religious organizations, but they are not widely publicized.[2]

Another important question is who owns these antibiotics and the resources to produce new ones? Public health in the United States is constrained by a highly proprietary approach to pharmaceuticals. Others have noted that the profit motive drives most decisions about research and production. This creates a bias toward the development of new drugs that treat chronic illnesses so that there will be a long-term market for them. New drugs for diabetes are a prime example.

In the case of new antibiotics, there is less incentive, since new products would be used only as long as the infection is present and then discontinued. They would probably be kept as a last resort and so there would not be a strong market demand for them.

Other options might include calling on international health groups or even on single governments to fund development. But in the U.S., attitudes toward government involvement in health care and budget cutbacks make this unlikely.

What about our responsibility to future generations? In their analysis of the ethics of microbial resistance Jasper Littmann and his colleagues cite global solidarity and hint at eschatology as they talk about our responsibility to the future:

> In addition to expanding our scope of care and concern beyond our own citizens and national borders to low and middle-income countries we also need to recognize that our current actions and policies will affect our microbial environment to such an extent that we have to include both current and future populations as part of our AMR response. The possibility of an impending post-antibiotic era means that future generations face a risk of being significantly worse off if bacterial infections can no longer be treated effectively, and it raises questions about the obligations we have to future people to preserve effective antibiotics.[3]

The issue here, they go on to say, is "whether persons who do not currently exist can make claims on current persons." This is a difficult question, since we have a hard enough time determining what justice claims living people can make on one another.

Another question is who would allocate new medications, and on what basis. Would they go to the sickest, the richest, the most influential? Would their use be limited to prosperous industrialized countries where they are likely to be developed? What would happen if an effective drug happened to be discovered in a developing country? Would that country be allowed to retain ownership of it and profit from it? (This is not as unlikely as it seems. Many antibiotics come from dirt, and focused research is taking place that analyzes dirt to find anti-microbial agents[4]).

These are classic rationing questions. At least in the U.S., we are not accustomed to thinking that there won't be enough of one commodity. The possibility of rationing is rarely even mentioned by politicians and policy makers, let alone considered as part of a health care policy.

There are resources in the Catholic tradition that can help us think through these dilemmas. First of all is the notion of justice and what Pope Benedict referred to as "the universal destination of human goods." Pope Francis used this idea to talk about the environment. It is our home, it belongs to all of us, and therefore all of us have a duty to protect it. The skills and resources of health care, like the environment, belong to us all; they are the result of massive human collaboration, suffering, and learning over the centuries. Even though there are some key players who deserve compensation for the research that led to these discoveries, they do not radically own them.

Another resource is our notion of the communion of saints. This is a belief that we are in solidarity with the living and the dead and that all of us together seek a common home in God, who is our source and our eternal destiny. If we believe that, then we do have an obligation to future generations, and we do have a duty to protect these essential goods of creation for their use.

This solidarity with the saints extends to our lives on earth as well. Unless our view of the human person is radically monistic, we must acknowledge that we share the condition of human frailty and mortality with everyone else, whether or not we know them personally. This view of solidarity leads us to say that if one of us is suffering, we all suffer. This is especially apparent in pandemics where another person's illness puts me at direct risk: their illness today could become my illness tomorrow. Infectious disease is a stark and unpleasant aspect of human solidarity.

Our view of the role of government is also important. If government is seen as a necessary evil, then the less of it the better. The Catholic tradition is more sanguine about the role of government than some. With due respect for subsidiarity, we see government as a necessary tool for maintaining peace and assuring basic human needs like health care and education. It seems to me that responsible government agencies with a lot of public involvement are the only bodies with enough money and resources to develop new antibiotics and prevent their misuse.

Insurance Coverage and Transgender Care

Insurance coverage is just one of the ethical issues in the multi-faceted question of health care for transgender persons. For every element of care – from a broken arm or cancer, to pre-and post-transition hormone treatment, psychotherapy and surgery, there is a corresponding question about who will pay.

Insurance coverage for transgender care, and particularly for procedures related to transition, is relatively new. In fact, expansion of coverage may itself be a significant factor in growing public awareness of transgender persons, especially as they gain access to more extended treatment.

The history of insurance funding for transgender procedures is recent. It was first funded by Medicare only in 2013; the Veterans' Administration announced they would fund some procedures in early 2016, but in November of the same year dropped their plans to do so. They did not drop the payments for ethical or medical reasons, but rather for budgetary reasons. Their November 14, 2016 statement said that since 1999 the VA has "provided many services for transgender veterans that include hormone therapy, mental health care, preoperative evaluation and long-term care following surgery," even if they do not provide surgical procedures.[5]

Many states (e.g., Oregon, California, Vermont, Connecticut, Massachusetts, Washington, Illinois, New York and the District of Columbia as of 2015) have passed non-discrimination laws that require insurance companies to provide transgender health coverage. A number of private insurance companies have begun covering transgender procedures when they determine them to be "medically necessary." Aetna, for example, has provided some coverage since 2009; it currently covers hormone therapy and psychological counselling and some surgeries. Their website[6] lists the following criteria for "medical necessity" for mastectomies for female-to-male patients:

a) A single letter of referral from a qualified mental health professional;
b) Persistent and well-documented gender dysphoria;
c) Capacity to make a fully informed decision and to consent to treatment;
d) Age of majority (18 or older);
e) Control of significant medical or mental health concerns.

Requirements for *hysterectomies and gonadectomies (*oophorectomy or orchiectomy*)* are similar but require two referral letters and at least twelve months of continuous hormone therapy.

Requirements for *genital reconstructive surgery* include everything above plus 12 months living in a gender role that is congruent with the patient's gender identity.

Children present a special case both because of consent issues and because of unknown long-term effects of hormone therapy before puberty. For these reasons, insurance coverage for those under 18 appeared later. According to one study, only in 2015 were all requests for puberty blockers approved by insurance for patients.[7]

These developments present several challenges for Catholic health care. First of all, rapidly expanding coverage by government and private insurance lends credibility to claims for care by transgender persons. Second, increased coverage is based on an implicit anthropology that sees human sexuality and gender as fluid, possibly variable and not irrevocably determined by phenotype. This view contrasts sharply with the traditional Catholic view. The fact that insurance companies are providing coverage certainly does not mean that these treatments, or even the diagnosis, are clinically appropriate or morally acceptable. But changes in attitude and protocols challenge ethicists to expand our inquiry into actual clinical experience and to begin to formulate an educational strategy that helps our providers to better understand the theological implications of transgender care.

Geriatric Sexuality

These two words might have at one time seemed like the title of a comedy film. Indeed in 1992 there was a film adaption of Muriel Sparks' novel "Memento Mori" about a group of elderly people (including Maggie Smith, Stephanie Cole and Michael Hordern, all of whom you would recognize as stellar British actors). The story revolves around their reactions to a mysterious caller who says simply, "Remember that you must die." Some react with fear, others with indifference, others with humor. But the film also contains some hints of how the elderly residents dealt with sexuality.

As our life expectancy grows, many of us will have the opportunity experience a second or third generation of sexual feelings. This is a private and personal issue that would ordinarily involve one's confessor or spiritual director. It is another thing entirely for persons in communal living arrangements, from assisted living to skilled nursing.

It is entirely natural for senior citizens to continue to desire and seek out intimate relationships. Friendships are the most important thing in life, and we appreciate them more as we age. Sometimes these relationships are a remedy for loneliness that is a part of old age. This is exacerbated by the loss of a spouse.

Children of elderly parents are sometimes surprised, and usually amused, to see that their mom or dad has taken up with a new companion. Staff sometimes find themselves in an awkward position if they are aware of shared afternoon naps or evening visits that last well into the night. Are they complicit in non-marital sex or even adultery if the spouse of one of the partners is disabled? Are they obligated to intervene? Should they tell family, or keep the secret?

These incidents can be complicated by routine memory loss or loss of inhibition. They become more serious ethically when true dementia sets in. There is literature on these questions including suggestions from the National Institute on Aging.[8] There are also resources for spouses of Alzheimer's patients, who sometimes complain their needs and their ability to cope with the changed circumstances of their marital relationship are not taken into account.[9]

Douglas Wornell, M.D. surveys the ethical issues surrounding sexuality in dementia patients. He notes that while sexual desire "often diminishes as dementia progresses," there can still be instances of disrobing, masturbation, or inappropriate sexual aggression.[10]

He says that forbidding residents of care facilities to express their sexuality, especially with a spouse, may be abusive; however, it is also possible that *allowing* them to engage in sexual activity with a spouse suffering from dementia may be abusive, especially if memory loss is so severe that the spouse is no longer familiar to the patient. If the patient is no longer able to recognize his or her spouse, an attempt at sexual activity, even within marriage, could be considered a form of rape.[11]

Three or four ground rules may be helpful.

a) Education is essential, both for staff and families, so they know what to expect. Families should be advised at admission of the possibility of sexual acting out as the disease progresses. Families and supervisors should be notified if there are instances of inappropriate behavior.

b) Respect the marital relationship as far as possible. The church is committed to protecting this privileged, sacramental form of friendship at all costs. Its conjugal expression should only be limited as necessary because of privacy concerns or because of concerns about consent.[12]

c) Non-marital or extra-marital *friendships* are natural and probably contribute to the patient's spiritual and mental health. These should be celebrated as long as they appear to be healthy and non-coercive. Non-marital *sex* should not be encouraged; however, this may be difficult to monitor or control in the relative independence of an assisted living facility if residents have individual apartments.

d) Adequate spiritual care for residents and patients is important to help them integrate their sexuality into their spiritual lives as they age. Sexuality may not have the same urgency in old age as it does for teenagers, but it is nonetheless an important aspect of human existence and should not be ignored.

Access to Health Care during Medicaid Expansions

As I write this, the Senate is in the process of re-writing the Affordable Care Act so that funding for Medicaid expansion will probably be severely limited going into the future. One of the arguments for this change is that the Affordable Care Act (aka Obamacare) has failed. But at least one study suggests otherwise.

One of the problems that the Obama administration set out to address with the Affordable Care Act was the problem of access to care. Until then, no insurance meant no access to care except through the emergency room. So expanded access to care is a key indicator of the success of the reform.

Sara Miller and Laura Wherry studied 60,766 U.S. citizens who qualified for insurance coverage because they were at or below 138 percent of the federal poverty level.[13] They compared those in states with Medicaid expansion with those in states that did not accept expansion funds. They found a significant decrease in reports of inability to afford needed follow-up care, and reduced worry about paying medical bills. A much smaller study in Massachusetts showed clear gains in coverage, but less clarity about access to care. However, they also found increased waiting times for care, which is probably the result of the inadequate number of primary care providers.[14] This problem has been noted in other places where access was expanded.[15]

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[1] The plague is not just a historical curiosity. For a contemporary outbreak, see "Plague is Found in New Mexico. Again." *New York Times* June 27, 2017. https://www.nytimes.com/2017/06/27/science/plague-is-found-in-new-mexico-again.html?

[2] For example see *Global Health and the Future Role of the United States*, The National Academy of Sciences, May 2017. (www.national-academies.org/USglogalhealth). The report highlights the importance of U.S. leadership in combatting AMR. A group of Catholic-inspired and other faith-based organizations met in Rome in December and issued a call to action. See "Combating the Emergence and Spread of Antimicrobial Resistance: A Workshop to Strengthen Faith-Based Engagement" (12-15 December 2016).

[3] Jasper Littmann and A.M. Viens, "The Ethical Significance of Antimicrobial Resistance" *Public Health Ethics* 8, 3 (2015) 209-244, at 217. See also Thomas O'Meara, "Catholic Health Care's Ministry to the Future," in *Incarnate Grace: Perspectives on the Ministry of Catholic Health Care.* St. Louis: Catholic Health Association (forthcoming fall, 2017). O'Meara explores the eschatological dimensions of our ministry.

[4] In 2015, researchers found a new antibiotic in dirt. See Anna Azvolinsky, "New Antibiotic from Soil Bacteria", *The Scientist*, January 7, 2015. http://www.the-scientist.com/?articles.view/articleNo/41850/title/New-Antibiotic-from-Soil-Bacteria/

[5] Rebecca Kheel, "VA Drops Plans to Cover Surgery for Transgender Vets," *The Hill* (November 14, 2014).

[6] "Gender Reassignment Surgery", http://www.aetna.com/cpb/medical/data/600_699/0615.html; accessed 6/30/2017.

[7] Jamie Stevens, Veronica Gomez-Lobo, and Elise Pine-Twaddell, "Insurance Coverage of Puberty Blocker Therapies for Transgender Youth" *Pediatrics* (136:6 December 6, 2015). The authors note that the most effective puberty blockers are gonadotrophin-releasing hormones (GnRH) agonist leuprolide (Lupron by AbbVie) or histrelin subcutaneous implants (Supprelin or Vantas from Endo Pharmaceuticals).

[8] "Changes in Intimacy and Sexuality: Alzheimer's Caregiver Tips", https://www.nia.nih.gov/alzheimers/publication/changes-intimacy-and-sexuality (accessed 7/6/2017); see also a Factsheet on Sex and Intimate Relations published by the Alzheimer's Society (Great Britain), (http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1801

[9] "Sexuality and Dementia," Family Caregiver Alliance (https://www.caregiver.org/sexuality-and-dementia)

[10] "Sexuality and Dementia," *Today's Geriatric Medicine* 7:2 (March /April 2014), 24:26 at 26.

[11] James Beauregard describes one such case, *State of Iowa v. Henry Vincent Rayhons*, involving a charge of sexual abuse of his wife in the third degree. See "Sexuality, Dementia and Catholic Long Term Care," *National Cath Bioethics Quarterly* 15 (Autumn 2015): 493-514, at 495ff.

[12] Beauregard gives a good overview of how to assess capacity for consent in the above article, at 504.

[13] "Health Care Access to Care During the First 2 Years of the ACA Medicaid Expansions." *NEJM* 376:10 (March 9, 2017): 947-956.

[14] Danny McCormick, MD, MPH, Assaad Sayah, MD, Hermione Lokko, BA, Steffie Woolhandler, MD, MPH, and Rachel Nardin, MD, "Access to Care After Massachusetts' Health Care Reform: A Safety Net Hospital Patient Survey", J Gen Intern Med. 2012 Nov; 27(11): 1548–1554. Published online 2012 Jul 24. doi: 10.1007/s11606-012-2173-7. "Access to care improved less than access to insurance following Massachusetts' health care reform. Many newly insured residents obtained Medicaid or state subsidized private insurance; cost-related barriers to access were worse for these patients than for the privately insured." This may have been in part due to cost sharing which was an obstacle for low income patients.

[15] Massachusetts Medical Society, "MMS Study Shows Patient Wait Times for Primary Care Still Long: Half of Primary Care Practices Remain Closed to New Patients; Wide Variations in Wait Times Among Massachusetts Counties", July 15, 2013.

OF NOTE

Students from the Saint Louis University School of Law Center for Health Law Studies contributed the following items to this column. Amy N. Sanders, associate director, supervised the contributions of Drew Canning (J.D. anticipated Dec. 2018) and Merlow Dunham (J.D./MHA anticipated 2019).

Appeal of Medicare Payment Rule Splits Circuits

The U.S. Court of Appeals for the District of Columbia determined that a Medicare payment rule impacting disproportionate share hospitals was not exempt from standard notice and comment procedures. The payment rule counted Medicare Advantage patients as entitled to Part A benefits, thereby reducing reimbursement for indigent care, and was effective 2014. However, the U.S. Department of Health and Human Services (HHS) disregarded public notice and comment, arguing the payment rule was exempt under the Administrative Procedure Act's (APA) interpretive rule provision. Breaking with the First, Sixth, Eighth and Tenth Circuit, the D.C. Circuit through Judge Brett Kavanaugh's opinion, stated the APA exception does not apply to the Medicare Act. Additionally, the D.C. Circuit split with the 9th Circuit on the issue of reviewability of expedited judicial review orders granted from the Provider Reimbursement Review Board (PRRB). In the July 25th ruling, the D.C. Circuit found providers are guaranteed expedited judicial review when the PRRB determines they have no authority to hear the appeal. HHS may decide to pursue a rehearing with the D.C. Circuit, petition the U.S. Supreme Court, or implement the appeals court ruling. Eric Topor, *BNA,* July 26, 2017 https://www.bna.com/hospitals-score-big-n73014462411/

Problem Solvers Caucus Hopes to Secure Health Exchange Market

Forty-four House of Representative members, named the Problem Solvers Caucus, are moving forward to "restore predictability" for insurance companies participating in the health exchanges. The 22 Republicans and 22 Democrats are petitioning committees that oversee areas of the Affordable Care Act to address key issues of stability. The bipartisan group's top goal is to appropriate reimbursement to insurance companies for covering low-income customers at reduced cost-share rates. The cost-share reduction funds have been challenged since 2014 when House Republicans withheld payments to health plans and successfully sued the Executive branch. Other items include sending money to states for reinsurance programs, applying the employer mandate to companies with 500 employees or more, and improving guidance on section 1333, which allows

insurers to sell health plans across state lines upon the agreement of state regulators. Currently the employer mandate impacts companies with 50 or more employees. Mara Lee, *Modern Healthcare*, July 31, 2017
http://www.modernhealthcare.com/article/20170731/NEWS/170739986/bipartisan-coalition-looks-to-solve-problem-of-individual-market

Cities Lose Health Marketplace Enrollment Support for 2018

Centers for Medicare and Medicaid Services (CMS) withdrew in-person health insurance enrollment support offered by two companies, McLean and CSRA Inc., for the 2018 marketplace open enrollment. The decision follows similar administration decisions such as implementing a shorter 45 day open enrollment period, as opposed to a 90 days, and cancelling advertising for the health insurance sign-up website HealthCare.gov. McLean and CSRA Inc. were awarded contracts in 2013 and operated in eighteen cities, focusing on sign-up assistance in libraries, business, and urban neighborhoods. The contracts contained a final option year which CMS elected not to renew and each will end services on August 29th. CMS continues to have a year-round call center and grant-funded sign-up programs. Impacted cities include Dallas, Houston, Miami, Tampa, Atlanta, Philadelphia, Chicago, Cleveland, New Orleans, Indianapolis, Charlotte, San Antonio, Austin, El Paso, Orlando, Phoenix, and Northern New Jersey. Carla K. Johnson, *Washington Post*, July 20, 2017
http://wapo.st/2gNrtqr?tid=ss_mail&utm_term=.a436ea15b94f

E-Cigarette Regulation Delayed, F.D.A Focuses on Nicotine

FDA Commissioner Dr. Scott Gottlieb announced a holistic approach to reduce tobacco deaths and nicotine addiction while postponing e-cigarette rules that would have required product approval. Public input will be sought to lower nicotine levels in combustible cigarettes to non-addictive levels. However, the commissioner will consider regulation of e-cigarette flavors aimed at children, such as Tutti Frutti and Banana Mash. Tobacco is the leading cause of preventable death, contributing to over 480,000 deaths a year, and the FDA views e-cigarettes as a possible cessation device because the vapor does not contain tar and other chemicals. The Tobacco Vapor Electronic Cigarette Association issued support for the new approach as well as the parent companies of Marlboro and R.J. Reynolds. Sheila Kaplan, *New York Times*, July 28, 2017
https://www.nytimes.com/2017/07/28/health/electronic-cigarette-tobacco-nicotine-fda.html

Medical Debt Will Have Delayed and Reduced Impact on Credit Score

Beginning September 15, Experian, Equifax, and TransUnion will institute a 180-day waiting period before medical debt appears on consumers' credit report. Also, the three major credit reporting agencies will remove medical debt from credit reports when it is paid by insurers. These updates arrive as FICO's newest credit-scoring model differentiates medical and non-medical debt, with the latter receiving smaller penalties in scoring. The change by credit reporting agencies originates from a settlement with New York Attorney General Eric Schliemann as well as agreements with 31 state attorneys general to aid the 42 million consumers with medical debt. The Financial Hope Collaborative at Creighton University indicated that "without a standardized process, some bills get sent to collections because they're 30 or 60 days past due." Additionally, the Financial Protections Bureau listed the average medical debt in collections as $579. Michelle Andrews, *Kaiser Health News*, July 11, 2017

http://khn.org/news/your-credit-score-soon-will-get-a-buffer-from-medical-debt-wrecks/

Hospital Systems Await States' Approval for Monopoly, Avoid FTC

Mountain States Health Alliance and Wellmont Health Systems, located along the Tennessee and Virginia border, await those states' approval of their merger that would create a thirteen-county monopoly on health services. The attempted merger would avoid Federal Trade Commission scrutiny by utilizing a Certificate of Public Agreement (COPA) available in the states of Virginia and Tennessee. Their plan requires regulators in each state to determine if the merger is in the public interest and then each state would govern parts of the company going forward, including price setting. Revenue gained from the combined entity would need to be used on public health concerns such as obesity and smoking. Since the 1940s, COPA use in hospital mergers has occurred less than fourteen times, including in nearby Asheville, North Carolina and last summer in West Virginia. Studies by economists indicate consolidation means higher prices, however Mountain States and Wellmont argue the merger will allow them to focus on care the community needs as opposed to services that produce highest profits. The FTC has condemned the plan by dismissing promises made by the companies and indicating many of the health systems goals can be achieved without the merger.

Likewise, area residents question the move. About 17,000 employees await the COPA decision.
Phil Galewitz, Kaiser Health News, July 24, 2017
http://khn.org/news/in-appalachia-two-hospital-giants-seek-state-sanctioned-monopoly/

Judge Strikes Down Alabama Law Putting Pregnant Minors Through Trial

A federal magistrate judge held that a unique law in Alabama imposes "an undue burden" on girls seeking permission to have an abortion through a judicial bypass procedure, wherein a minor who lacks parental permission for an abortion can instead obtain a court's permission. The judicial bypass is a trial-like proceeding where a judge may appoint a guardian ad litem to represent the interests of the fetus, and the minor is questioned in court to determine whether she is mature enough to make an informed decision to have an abortion without parental consent. The judge sided with the American Civil Liberties Union of Alabama, which argued that because a judicial bypass enables state attorneys to subpoena the girl's teachers, friends, family, etc. to testify about her maturity, the girl's right to confidentiality is violated and she is exposed to potential physical and mental abuse once her wish to abort is made known to others in her life. The judge noted that she knew of no other state with such a law. The Associated Press, *The New York Times*, July 31, 2017
https://www.nytimes.com/aponline/2017/07/31/us/ap-us-abortion-law-alabama.html?utm_campaign=KHN%3A%20First%20Edition&utm_source=hs_email&utm_medium=email&utm_content=54831764&_hsenc=p2ANqtz-9-1WZ7zTe8FkQr53QXj7rH6Sv6Hlr7lSiHK_2MoqIvW-b-WfF6FnUzrwSiuU1M401RMJfIHhddw8rnqi_rHCTUyac3oA&_hsmi=54831764

Trump Cites Health Care Costs Among Reasons for Not Allowing Transgender People in the Military

President Donald Trump announced that transgender individuals will no longer be allowed to serve in the United States military out of concern for "tremendous medical costs and disruption" that would result. The declaration via Twitter was made in response to a dispute over whether taxpayer money should be used to pay for gender transition and hormone therapy for service members who identify as transgender. A 2016 RAND Corporation study commissioned by the Pentagon estimates that between 2,000 and 11,000 active-duty service members are transgender. This same study concluded that openly transgender service members would increase health care costs from $2.4

million to $8.4 million, a mere 0.04 to 0.13 percent spending increase. While some conservative lawmakers have supported the president, many civil rights and transgender advocacy groups have expressed outrage and the president's decision is likely to end up in court. Julie Hirschfeld Davis and Helene Cooper, *The New York Times*, July 26, 2017
https://www.nytimes.com/2017/07/26/us/politics/trump-transgender-military.html

World Health Organization Releases New List of "Reserve" Antibiotics, Used to Combat Superbugs

The World Health Organization (WHO) released new categories of antibiotics in an effort to increase the reserve of "last resort" drugs used to combat superbugs. WHO cites overuse of antibiotics in humans and livestock as the main reason behind the increasing number of new pathogen strains that are resistant to traditional antibiotics. The WHO advises that antibiotics are placed in one of three categories – access, watch, and reserve – to designate which drugs can be used more regularly and which should only be used as a "last resort." The "access" category includes common antibiotics like amoxicillin that should be "available at all times." The "watch" category includes antibiotics such as ciprofloxacin that should only be used when needed. The third "reserve" category includes antibiotics like colistin that are the last line of defense and should only be used "in the most severe circumstances when all other alternatives have failed." The newly-categorized lists of antibiotics can be found in the WHO's Model Lists of Essential Medicines for 2017, which is revised every other year to provide guidelines for the drugs that each country should keep in stock. Ariana Eunjung Cha, *Modern Healthcare*, June 6, 2017
https://www.washingtonpost.com/news/to-your-health/wp/2017/06/06/who-creates-controversial-reserve-list-of-antibiotics-in-new-response-to-superbug-threats/?tid=a_inl&utm_term=.370c9bd6c9d4

Accountable Care Organizations and Alternative Payment Models Grow in 2017

A recent *Kaiser Health* study shows that accountable care organizations (ACOs) and alternative payment models (APMs) continue to grow in 2017. In the past year in the United States, there was an increase in 2.2 million lives covered by an ACO, meaning over ten percent of the population is currently covered by an ACO. Commercial ACO contracts tend to cover the most lives (715 contracts, 59 percent of covered lives), followed by Medicare contracts (563 contracts, 29 percent of covered lives), followed by Medicaid contracts (88 contracts, 12 percent of covered lives). ACOs currently exist

in every state as well as Washington D.C. and Puerto Rico. Similarly, there has been increased growth in APMs, likely due to the passage of the Medicare Access and CHIP Reauthorization Act (MACRA), which provides incentives for physicians to join APMs. The majority of APM participants are involved in the medical home model (2,891 participants), followed by the episode-based model (792 participants), followed by the ACO model (480 participants in traditional Medicare Shared Savings Program ACOs, and 45 participants in Next Generation ACOs). David Muhlestein et al., *Health Affairs*, June 28, 2017
http://healthaffairs.org/blog/2017/06/28/growth-of-acos-and-alternative-payment-models-in-2017/

Veterans Health Administration Proves Successful in Increasing Veterans' Hospice Use

The Comprehensive End of Life Care Initiative, a four-year investment implemented in 2009 by the Department of Veterans Affairs (VA) aimed at improving the quality of end-of-life care for veterans, has proven to be effective as reflected by increased hospice use. In the first two years following implementation, the initiative resulted in the establishment of fifty-four new hospice and palliative care inpatient units. A recent study published in *Health Affairs* shows that the initiative successfully increased rates of hospice use among male veterans age sixty-six and older. The initiative's impact has been felt beyond the VA system, as it also resulted in over 3,000 community hospices making commitments to improve the quality of end-of-life care for veterans. This study demonstrates the impact that the VA system can have on increasing the quality of end-of-life care for veterans, even within a short duration of time. Susan C. Miller et al., *Health Affairs*, July 2017
http://content.healthaffairs.org/content/36/7/1274

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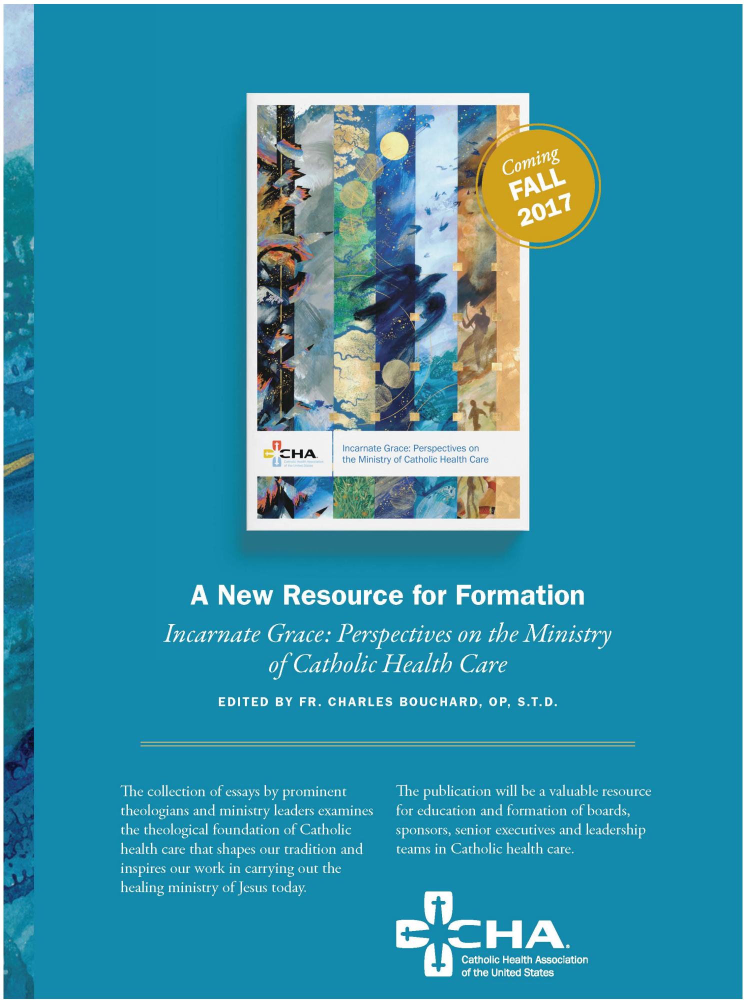

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