

# Health Care Ethics USA

A quarterly resource for the Catholic health ministry

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## In This Issue

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### Feature Articles

PAGE 1

Pope Francis and the Zika Virus  
*Rev. Gerald D. Coleman, S.S., Ph.D.*

PAGE 7

Viewing the Transgender Issue from the Catholic  
and Personalized Health Care Perspectives  
*Kevin FitzGerald, S.J., Ph.D., Ph.D.*

### Ethical Currents

PAGE 11

### Of Note

PAGE 15

# Pope Francis and the Zika Virus

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During a press conference on Feb. 18, 2016 on a flight from Juarez, Mexico to Rome, a reporter questioned Pope Francis about the growing concern in many Latin American countries and Europe about the Zika virus and its risks for pregnant women. The reporter asked: "Holy Father, for several weeks there's been a lot of concern ... regarding the Zika virus. The greatest risk would be for pregnant women. There is anguish. Some authorities have proposed abortion, or else to avoiding pregnancy. As regards avoiding pregnancy, on this issue, can the Church take into consideration the concept of 'the lesser of two evils?'"<sup>1</sup>

Pope Francis unequivocally condemned the abortion option: "Abortion is not the lesser of two evils. It is a crime. It is to throw someone out in order to save another. That's what the Mafia does. It is ... an absolute evil." He then added, "On the 'lesser evil,' avoiding pregnancy, we are speaking in terms of the conflict between the fifth and sixth commandment. Paul VI, a great man, in a difficult situation in Africa, permitted nuns to use contraceptives in cases of rape."

Critics of the Pope's remarks raise grave concerns regarding his opinion. They most often cite *Humanae Vitae* which prohibits "any action which either before, at the moment of, or after sexual intercourse, is specifically intended to prevent procreation" (no. 14) The critics conclude that using condoms to reduce the likelihood of Zika transmission amounts to directly intending contraceptive acts of intercourse as a means

to a good end. Consequently, "the Pope has asserted something that is false and contrary to salvation."<sup>2</sup>

In light of Pope Francis' comments and the criticisms they have received, I would like to offer a modest review of cases that raise questions about the use of contraceptives and hopefully situate the Pope's remarks.

## The Belgian Congo Controversy

Moral and pastoral concerns arose in the early 1960s regarding the plight of religious sisters and other women caught up in the uprisings in the Belgian Congo. These women were given anovulant drugs by "doctors on the mission" in order to ward off pregnancy which might otherwise result from rape which was a constant threat in that chaotic time. These physicians and their moral advisors did not consider their action either contraception or direct sterilization in the sense in which the church stood against such interventions for the prevention of pregnancy.

Eminent Roman moralists Palazzini, Hurth, Lambruschini and Zalba addressed this plight by asking whether or not a nun or any woman who reasonably fears she may be raped can take progestational drugs to induce temporary sterility to prevent a possible conception?<sup>3</sup> The nuns, of course, had no intention of consenting in any way to the

action violently imposed on them. These theologians gave positive replies by appealing to the principle of legitimate self-protection.

Marcellino Zalba, S.J. was a strong defendant of *Humanae Vitae* and along with John Ford, S.J. persuaded Pope Paul VI to reject the recommendations of the majority opinion of the papal commission on contraception. On the issue at hand, however, he wrote "the intention ... is not the interruption of ovulation but the prevention of the consequences of a ... violation of chastity." The nuns were protecting themselves from physical and emotional disorder created by fear. Due to this "good motive," these moralists concluded that the medical intervention constituted only "indirect sterilization." Consequently, the nuns incurred no moral culpability as all the blame and responsibility rested on the shoulders of the person violating them.

These theologians explained that direct sterilization condemned by the magisterium as intrinsically evil is the direct sterilization ordered to the prevention of procreation in persons who *want* to exercise their sexual function. The nuns under threat of rape acted morally by ingesting progestational drugs as they had no intention to voluntarily exercise their sexual capability.

Zalba concluded, "We can assert with full conviction that pontifical doctrine does not exclude the putting of physical functions, even those which as functions are quite normal, at the service of the legitimate interests of the acting person. This may be done in order to ward off from the body itself hardships which are being imposed upon the person contrary to the person's will. Or it may be done to deliver the soul and the spirit from calumny, rejection, social difficulties, etc. Or it may be done so that the person may enjoy simply the condition of liberty which the

person does not want to give up." Zalba is advocating an application of the principle of self-defense.

In his Apostolic Exhortation *Familiaris Consortio* (1981), Pope St. John Paul II insisted that the conjugal act is both a sign (openness to procreation) and a language ("We love each other as only a husband and wife can"). When the internal commitment to conjugal love is revoked or made inoperable, the conjugal act itself is counterfeited and bereft of moral dignity. When a conjugal act is forced upon a woman, the language of love is not present and thereby contradicted.

This moral tradition amounts to what is called "solidly probable opinion" that a woman who cannot escape sexual oppression may licitly resort to artificial means to avoid a pregnancy from sexual acts forced upon her. In their extensive study of this question, Ambrogio Valsecchi in *Controversy: The Birth Control Debate* and Edward Bayer in *Rape Within Marriage* conclude, "This acceptance ... has been carefully reviewed by the teaching authority of the Church without any objections whatsoever."

### HIV/AIDS and the Use of Condoms

At the time of Pope Benedict XVI's 2009 visit to Africa, about 30.8 million adults and 2.5 million children worldwide were living with HIV. Sub-Saharan Africa was the region most affected. Even though this region has just over 10 percent of the world's population, it is home to 68 percent of all people living with HIV/AIDS. An estimated 1.8 million adults and children became infected with HIV during 2009, contributing to a total of 22.5 million people living with HIV in the region. Southern Africa accounts for around 40 percent of the global total of women living with HIV.

In an interview with reporters during Pope Benedict's March 17 flight to Cameroon, a French journalist commented that among the many ills that beset Africa, "one of the most pressing is the spread of AIDS." The journalist asked the Pope if he agreed that "the position of the Catholic Church on the way to fight it is ... unrealistic and ineffective?" The Pope replied, "Just the opposite."

Benedict pointed out that "the most efficient [and] truly present player in the fight against AIDS is the Catholic Church herself." He went on to say that the "problem of AIDS" cannot be overcome merely with money, "if there is no human dimension, if Africans do not help [by responsible behavior], the problem cannot be overcome by the distribution of prophylactics."

In *Light of the World: The Pope, the Church, and the Signs of the Times* (2010), the Pope returned to the subject of HIV/AIDS and condom use. He re-emphasized the importance of the "humanization of sexuality" as the foremost way of combating HIV/AIDS. He added, "we cannot solve the problem by distributing condoms. Much more needs to be done" as the distribution of condoms is not "a real or moral solution, but, in this or that case, there can be nonetheless, in the intention of reducing the risk of infection, a first step in a movement toward a different way, a more human way, of living sexuality."

Federico Lombardi, S.J., director of the Holy See Press Office, explained that the Pope's remarks "cannot be defined as a revolutionary shift" in church teaching. He pointed out that "numerous moral theologians and authoritative personalities have sustained, and still sustain, a similar position."

On Dec. 21, 2010, the Congregation for the Doctrine of the Faith (CDF) issued a "Note on the Banalization of Sexuality Regarding Certain

Interpretations of 'Light of the World.'" It explains that Benedict's remarks were aimed at rediscovering "the beauty of the divine gift of human sexuality" and do not represent "a change in Catholic moral teaching or in the pastoral practice of the Church." The CDF stated that "those who know themselves to be infected with HIV and who therefore run the risk of infecting others, apart from committing a sin against the sixth commandment are also committing a sin against the fifth commandment – because they are consciously putting the lives of others at risk through behavior which has repercussions on public health." The Note concludes that "those involved in prostitution who are HIV positive and who seek to diminish the risk of contagion by the use of a condom may be taking the first step in respecting the life of another – even if the evil of prostitution remains in all its gravity."

The 2001 pastoral letter of the Southern African Catholic Bishops Conference similarly asserted that in a case of a married couple in which one spouse was HIV-positive and the other was not, the use of "appropriate" protection to prevent the spread of HIV was acceptable. They defended their position by affirming that everyone has a right to defend one's life against mortal danger.

Fr. Martin Rhonheimer, professor of ethics and political philosophy at the School of Philosophy of the Pontifical University of the Holy Cross in Rome, has upheld this same understanding, particularly in his 2004 article, "The Truth about Condoms." He argued that "a married man who is HIV-infected and uses the condom to protect his wife from infection is not acting to render procreation impossible, but to prevent infection. If conception is prevented, this will be an –unintentional – side-effect and will not therefore shape the moral meaning of the act as a contraceptive act."<sup>4</sup>

## The Zika Virus and Contraception

The Zika virus, first discovered in Uganda in 1947, was confined to the equatorial belt in Africa and Asia and thought to cause little more than mild flu-like symptoms. In 2007, physicians on Yap Island in Micronesia noticed an outbreak of the virus. In 2013 an outbreak in French Polynesia may have infected as many as 19,000 people and for the first time the virus was associated with neurological disorders. At some recent point, perhaps during the 2014 World Cup held in Brazil, an infected traveler brought the virus to Latin America where it has exploded, spreading to more than twenty countries and likely infecting hundreds and thousands of people. The virus has catapulted from obscurity into the spotlight.<sup>5</sup>

Of central concern is what the virus seems to be doing to pregnant women. Since the first case of Zika in Brazil in May 2014, the country has reported some 4,000 cases of microcephaly, a severe birth defect that causes an abnormally small head and minor to major brain damage in infants.<sup>6</sup> The causal relationship of the Zika virus to cases of microcephaly is presently under intense investigation, although a study published in the March 2016 edition of *The New England Journal of Medicine* claims "now there is almost no doubt that Zika is the cause."<sup>7</sup> Since Brazil is ground-zero for the virus, there is now serious talk of canceling the summer Olympic Games there and the U.S. Olympic Committee has warned athletes and staff to consider skipping the Rio Games.

There is a growing number of Zika cases in the U.S. in travelers who became sick elsewhere and brought the disease home.<sup>8</sup> There is no vaccine for the Zika virus, and no cure for microcephaly. On Feb.1, the World Health Association declared the Zika epidemic an international public emergency.<sup>9</sup>

Over the coming decades, global warming is likely to increase the range and speed of the life cycle of the yellow fever mosquito, *Aedes aegypti*, which carries the virus. *Aedes aegypti* is present across the southern tier of the U.S. Recent research suggests that the number of people exposed to the mosquito could more than double from roughly 4 billion today to as many as 8 to 9 billion by late 21st century.<sup>10</sup>

Public health officials are nearly certain that the Zika virus is behind Brazil's surge of babies being born with tiny heads and damaged brains, although proof is likely to take months at the very least. Researchers have been able to recover the entire Zika virus genome from the brain tissue of an aborted fetus with microcephaly, leading some physicians to take the position that the Zika virus is "guilty until proven innocent" for causing microcephaly. The director of the main hospital in Medellin, Columbia, goes so far as stating that any women whose fetuses show signs of the virus should be offered abortion.<sup>11</sup>

In his remarks during the Feb. press conference, Pope Francis said that avoiding pregnancy is not an absolute evil. As in the case of the nuns in the Belgian Congo, he understands the use of contraceptives in preventing the spread of the Zika virus as a "permitted case."

In an interview with Vatican Radio on Feb.19, Fr. Lombardi furthered the Pope's response by indicating that "Catholics with a well-formed conscience can decide to use contraceptives 'in cases of particular emergency.'" This decision must follow only after a "serious discernment of conscience."<sup>12</sup>

## Summary

These three cases are each situated in different but real-life situations: nuns in the Belgian Congo under the threat of rape, the overwhelming presence of

HIV/AIDS in African countries, and the pandemic of the Zika virus with its effects on children born of infected mothers. In the case of the nuns in the Belgian Congo, the use of anovulant drugs was seen as permissible in light of the principle of legitimate self-protection. The nuns who obviously did not seek sexual intercourse, used these drugs in order to protect themselves from physical, emotional and religious fear and anguish.

In the case concerning HIV/AIDS in Africa, the use of a condom was considered appropriate, although not ideal. The aim was the prevention of infection rather than a direct intent to render procreation impossible.

In the current concerns about the Zika virus present in pregnant women and its link to microcephaly, a husband with a well-formed conscience might use a condom to reduce the likelihood of Zika transmission. Ideally, a husband might abstain from sexual intercourse with his wife as long as she is infected, or employ the method of natural family planning. If these measures seem to be a moral impossibility<sup>13</sup> for a couple, the use of a condom in this case is justified under the traditional principle of double effect.<sup>14</sup> This moral principle is used in conflictual situations in which a single composite action (use of a condom) has at least two foreseen effects that cannot be separated: one that is good and intended (preventing Zika transmission) and a secondary and unintended effect (contraception).

The *Catechism of the Catholic Church* reminds us that the "spouses' union achieves the twofold end of marriage: the good of the spouses themselves and the transmission of life. These two meanings or values of marriage cannot be separated without altering the couple's spiritual life and compromising the goods of marriage and the future of the family." (no. 2363)  
The manner in which the dilemmas were addressed in

each of the case studies above does not deny or impinge this important teaching of the church about the true meaning of marriage. They rather demonstrate that in dire circumstances traditional moral principles such as legitimate self-defense and the lesser evil can appropriately be used. Contraception is, then, not always a sin.

<sup>1</sup> See James F. Keenan, "Pope Francis on Zika and Contraception," <http://americamagazine.org/content/all-things/pope-francis-zika-and-contraception>

<sup>2</sup> Laurie Goodstein, "Catholic Leaders Say Zika Doesn't Change Ban on Contraception," *New York Times*, February 14, 2016, 8. John-Henry Westen, "Pro-Life and Catholic Leaders Voice Grave Concern over Pope's Contraception Remarks," [lifesitenews.com](http://lifesitenews.com), February 23, 2016, "Zika Does not Justify Abortion or Contraception," National Catholic Bioethics Center, February 25, 2016, <http://mail.aol.com/webmail-std/en-us/PrintMessage>.

<sup>3</sup> See Ambrogio Valsecchi, *Controversy: The Birth Control Debate 1958-1968*, Washington, D.C.: Corpus Books, 1967, 26-36 and Edward Bayer, *Rape Within Marriage: A Moral Analysis Delayed*, Lanham: University Press of America, 1985, 82-92, 114-127.

<sup>4</sup> For a more complete discussion of Pope Benedict's remarks, see Gerald D. Coleman, "The Use of Prophylactics and the Principle of Gradualism," *Health Care Ethics USA* 19:1 (2011), 2-11.

<sup>5</sup> <http://www.asianscientist.com/tag.the-bug-report> and Bryan Walsh, *Why the Zika Outbreak Marks a New Normal for Infectious Disease*, *Time* magazine, February 8, 2016, 9 and February 15, 2016, 44.

<sup>6</sup> Donald G. McNeil and Catherine Saint Louis, "Two Studies Strengthen Links Between the Zika Virus and Serious Birth Defects," *New York Times*, March 5, 2016, A7.

<sup>7</sup> Donald G. McNeil, "Proof on Virus and Defects Is Expected to Take Months," *New York Times*, February 20, 2016, A5 and "The Potential Hidden Toll of Zika: Infants May Later Have Mental Health Issues," *New York Times*, February 23, 2016, D1.

<sup>8</sup> Sabrina Tavernise, "Officials Report 9 New Cases of Zika Virus Among Pregnant Women Tested in U.S.," *New York Times*, February 27, 2016, A14 and "Centers for Disease

Control and Prevention Investigating 14 New Reports of Zika Transmission Through Sex," *New York Times*, February 24, 2016, A3,

<sup>9</sup> Sabrina Tavernisi, "World Health Organization Urges Contraception in Countries with Virus," *New York Times*, February 19, 2016, A12.

<sup>10</sup> Justin Gillis, "In Zika Epidemic, a Warning on Climate Change: Mosquitoes Will Thrive in a Warming Climate," *New York Times*, February 21, 2016, 6.

<sup>11</sup> Nicholas Casey, "Pregnant and Facing Dilemma Over Zika," *New York Times*, February 16, 2016, A4.

<sup>12</sup> Joshua J. McElwee, "Francis Allows for Discernment on Contraception in Emergency Cases, Spokesman Says," *National Catholic Reporter*, February 22, 2016.

<sup>13</sup> See James T. Bretzke, "Impossibility," *Handbook of Roman Catholic Moral Terms*, Washington, D.C.: Georgetown University Press, 2013, 120.

<sup>14</sup> See *Catechism of the Catholic Church*, no. 2263 and St. Thomas Aquinas, *ST II-II*, Q. 74, art 7.

# Viewing the Transgender Issue from the Catholic and Personalized Health Care Perspectives

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In the Winter 2016 issue of *Health Care Ethics USA*, two feature articles explored some of the ethical issues surrounding the medical care of transgender persons, with a particular focus on the possible surgical interventions to “reassign” a person’s sexual features.<sup>1</sup> It is not my purpose to revisit the good work done by both authors on this topic, but to use their insights and arguments to reframe this issue in light of the 21<sup>st</sup> century approaches to health care and medical science that I have cited before in both *Health Progress* and in presentations for CHA.<sup>2</sup>

These frameworks—such as personalized health care, precision medicine, and systems biology— focus on integrating data and insights from a broad array of disciplines and arenas in order to obtain a more comprehensive and nuanced understanding of each patient’s health situation and the most likely treatments or interventions that will preserve or enhance that patient’s health.

## Complexity of Sex, Gender and Human Nature

One reason for seeking a different perspective on this issue is the growing awareness of the multiple biological and social factors that potentially contribute to a person’s sense of sexual and gender expression. These factors include genetic, epigenetic,<sup>3</sup>

neuroanatomical, endocrine, fetal development, and the entire array of positive and negative social experiences one can have from birth onwards. This etiological complexity of sex and gender identification is in stark contrast to the traditional manner of sex/gender identification at birth (i.e. does the baby look male or female). For the vast majority of human beings, the traditional approach has worked, so why be concerned about this issue of sex and gender identification now?

Aside from the relatively recent political and social attention being paid to transgender issues, there is good medical reason to be attentive to this area of health care. First of all, as cited in my previous article in *Health Progress*, the rapid progress of biomedical research will uncover surprising aspects of our human nature that run counter to our everyday concepts of health and normalcy.<sup>4</sup> Apparently, from recent research into the issue of the experiences of people who identify as transgender, as well as other research in sexual behavior and identification, the complexity of human sexuality and sexual behavior may be much greater and more diverse than has been understood or appreciated. In fact, the traditional physical and behavioral differences we might easily associate with our female-male dichotomy may actually be more of

a spectrum of possible combinations between the two sexes/genders than we have previously thought. This complexity is such that even experienced health care providers and researchers working with people who identify as transgender acknowledge the current lack of clarity regarding medical research, diagnoses and treatment outcomes.<sup>5</sup>

In one sense, these research results should not be that disruptive of our traditional concepts of male and female. Health care workers have been aware of babies born with ambiguous genitalia since the beginning of health care. The potentially disruptive part of recent research is the complexity of factors that may significantly affect a person's experience of one's sex and gender, and the complexity those interacting factors may have on experience.

### Need to Update Our Understanding

In light of the research and our commitment to provide the best health care to all, we need to update our understanding of sexual characteristics and gender identification and the various ways in which both can be experienced and expressed in human beings.

This recognition of the need to update our understanding of human nature is not new within our Catholic tradition. The Catholic Church has a long history of integrating scientific advances into its understanding of Creation and human nature. In fact, advances in the understanding of human embryology that occurred in the 17<sup>th</sup> to 19<sup>th</sup> centuries helped inform the decision by Pius IX in 1869 to clarify the moral reasoning for acknowledging a human embryo as a human being from the time of conception.<sup>6</sup> With the lack of clear scientific evidence to inform medical decision-making especially on an institutional level, and the opportunity to apply improved medical research frameworks to this issue, it may be time for Catholic health care to investigate

how our understanding of human sexuality and gender might be advanced in order to better respond to the political dynamics of our time, and, more importantly, better address the needs of patients.

### Research Design

One aspect of the systems approach to medical research that integrates well with Catholic health care is the need to take a broader view of the goals of the research before one undertakes designing research protocols. These goals include the patients' goods as well as the broader goods of society and humankind. Hence, it will be crucial from the outset to wrestle with issues such as the concepts of human nature that undergird the research (implicitly or explicitly), and the types of treatments or interventions that are as likely to be effective in addressing patient needs and suffering (again, implicitly or explicitly).

For instance, it can make a significant difference in how a research protocol is designed if the goal of the research is to better understand human diversity and how to help those who are not like most others to better integrate their own unique features within themselves and within society (including society integrating them well). This approach contrasts with a design focused on uncovering new data that could be used to whatever end anyone chose to use it. This could include selection of certain individuals with undesired characteristics in utero, or adding certain genetic choices to a range of options one can choose from as an autonomous agent (e.g. a parent of a child or an adult for one's self)—as long as one has the resources to do so.

In other words, health care and biomedical research are different if the goal of research and treatment focuses on the physiological and social features and goods of the research participant and patient, than if the focus is a more reductionistic one of discovering

the cause of, or fixing, a “problem” in the research participant or patient (physical or psychological).

This more reductionistic approach appears to be one of the problematic features associated with earlier research and treatment programs that focused on surgical interventions to solve patients’ problems.<sup>7</sup> These results stand in contrast to a different research approach that focused on children identified as transgender and living in supportive environments without undergoing surgical, physiologic or hormonal interventions.<sup>8</sup> The results of the latter study were summarized as: “transgender children showed no elevations in depression and slightly elevated anxiety relative to population averages.

They did not differ from the control groups on depression symptoms and had only marginally higher anxiety symptoms.”<sup>9</sup> Though obviously limited in its scope (children aged 3-12 from supportive families) and requiring additional larger and more complex follow-up studies to investigate its broader applicability, this research succeeds in raising the issue of the appropriateness and success of intervention or treatment plans that focus on more inclusive social support and acceptance (i.e. helping the children feel good about themselves as they are) rather than surgical or technical fixes that always entail the inherent additional risks and consequences of such interventions, and that focus on the goal of making the individuals physically more like a different type of person in hopes that will make the patient feel better about themselves. This surgical or hormonal approach runs the additional risk of limiting a child’s or adolescent’s ability also to come to the determination that one is not transgender after all.

From the perspective of personalized health care and the goals and values of the Catholic tradition, the approach of helping a person or patient to better understand, accept and adapt to their unique health

advantages and challenges would be the decidedly preferable approach. Of course, the reality for many patients is that they are already experiencing significant, or even severe, distress regarding their sense of discordance between how they see themselves and how they feel accepted within their community or society. However, even in these circumstances, one can question whether or not we have done the right kind of research and development of interventions and treatments that would work to provide the appropriate understanding and support for patients who find themselves at odds with cultural or social norms. In fact, this issue of caring for people who find that their sexual or gender experience of themselves in the bodies they have does not conform to their experience of how they seem to fit into society can be seen within a much larger cultural tension that affects the health of many people within our society.

Recent research has also indicated that many young adults—both male and female—experience an overall discontent with the shape and form of their bodies to an extent that can be detrimental to their psychological and physical health.<sup>10</sup> Hence, the larger issue may be that all of us live in an unhealthy society that pressures many, if not most, of its people to experience themselves as incorrect, inferior or even wrong in their current physical and psychological states. While some may be fortunate enough to find understanding and supportive families and communities to grow up and live in, many do not. These less fortunate individuals can then fall prey to societal pressures about ideal body types that are not healthy and do not truly serve their good—including supposed treatments and cures that only exacerbate their suffering.

This present situation is not in line with the goals of personalized medicine or Catholic health care, and must be addressed with sensitivity, care and determination to assist those who suffer from the

effects of this unhealthy aspect of our society. One place we can start is to encourage better understanding and care for any who feel ostracized or abused just for trying to live and grow into who they are, and help them resist societal pressures to harm themselves by trying to change physically, physiologically or psychologically into someone they are not.

<sup>1</sup> Carol Bayley, “Transgendered Persons and Catholic Healthcare,” *Health Care Ethics USA*, Winter 2016, Volume 24, Number 1, pp. 1-5; and Becket Gremmels, “Sex Reassignment Surgery and the Catholic Moral Tradition: Insight from Pope Pius XII on the Principle of Totality,” *Health Care Ethics USA*, Winter 2016, Volume 24, Number 1, pp. 6-10.

<sup>2</sup> Kevin FitzGerald, “The Challenges of Precision Medicine,” *Health Progress*, Sept-Oct 2015, and “Genomic Medicine and the Family,” *CHA Theology and Ethics Colloquium*, March 16-18, 2016, St. Louis, MO.

<sup>3</sup> [Editor’s Note: Epigenetics, in the field of genetics, is the study of cellular and physiological variations that are caused by external or environmental factors that switch genes on and off and affect how cells *read genes*. <https://en.wikipedia.org/wiki/Epigenetics>]

<sup>4</sup> Ibid.

<sup>5</sup> See: Dogu Aydin, et al., “Transgender Surgery in Denmark From 1994 to 2015: 20-Year Follow-Up Study,” *The Journal of Sexual Medicine*, Volume 13, Issue 4, April 2016, pp. 720–725; and <http://www.npr.org/sections/health-shots/2016/03/23/471265599/probing-the-complexities-of-transgender-mental-health>.

<sup>6</sup> DA Jones, “The human embryo in the Christian tradition: a reconsideration,” *Journal of Medical Ethics*, 2005 31: 710-714. [Editor’s Note: It also likely contributed to the Church’s declaration of the Immaculate Conception as an article of faith.]

<sup>7</sup> See footnote 5.

<sup>8</sup> Kristina R. Olson, et al., “Mental Health of Transgender Children Who Are Supported in Their Identities,” *Pediatrics*, Volume 137, number 3, March 2015.

<sup>9</sup> Ibid.

<sup>10</sup> Stacey Tantleff-Dunn, Rachel D. Barnes, and Jessica Gokee Larose, “It’s Not Just a ‘Woman Thing:’ The Current State of Normative Discontent,” *Eating Disorders* 2011 October; 19(5): 392–402; see also <http://psychcentral.com/blog/archives/2014/06/26/body-image-battles/>

## Hospice Care and Assisted Suicide: A Crisis of Identity and Mission?

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In 2014, Courtney Campbell and Margaret Black wrote a very thorough and helpful analysis of how hospices in Oregon and Washington understand their mission vis-à-vis assisted suicide.<sup>1</sup> They attempted to disentangle the mission and purpose of hospice – a fairly new development – from the even newer question of physician assisted suicide. Their research revealed several areas of tension in practice and in the ways in which hospices describe the relationship of their mission to the reality of legal assisted suicide. In the end, it comes down to whether hospices see physician assisted suicide as complementary to their mission of providing end-of-life care, or at odds with it. The article concludes with a set of “deliberation questions” grouped according to stakeholder interest and designed to help hospices clarify their understanding of PAS and how their mission relates to it.

Even though their article was published over two years ago, we are summarizing it here because of the possibility that PAS may be legalized states other than Washington, Oregon, and now California, in the near future.<sup>2</sup> We realize that a short summary carries the risk of inaccurately or incompletely representing the results of their study, but we believe that this article is a very good attempt to help hospices to clarify how they see PAS, both for their own integrity and for the benefit of patients, families and staff. Following the summary, I will describe a number of ethical questions that their research raises.

Their research focuses on “how hospice programs have interpreted their philosophy and mission to accommodate patient requests and the extent to which they may incorporate the process of physician-assisted death as part of the responsibilities of hospice caregiving.”<sup>3</sup> Their analysis includes setting a context for practices and policies of the hospitals in Washington state; presenting an overview of their theoretical framework; and focusing on four key issues.

They studied documentation from 33 hospices. Their initial analysis focused on nine key areas: 1) The background philosophy of hospice care; 2) the language used by the hospice to refer to patient requests for assistance in dying; 3) the policy or statement of position; 4) the values invoked by the hospice to support that position; 5) the practical processes used by a hospice upon receipt of a patient request; 6) the caregiving commitments of a hospice upon receiving a request; 7) the restrictions a hospice program placed on staff and volunteers; 8) the specific responsibilities or restrictions placed on staff regarding presence at a patient’s self-administration of medication; and 9) the independence or autonomy of the hospital relative to affiliation with hospitals and other organizations.

They distill these nine areas to four: 1) nomenclature used to describe the action legalized by the Washington Death with Dignity Act (WDDA); 2) values represented in the hospice policies; 3) position on staff presence; 4) position on staff participation.

*Naming the Issue.* Researchers found that Washington hospices use a variety of terms to describe what was legalized by the WDDA. These include physician assisted suicide, physician assisted death, physician

aid-in-dying, patient self-administration of a lethal medication, and hastening death. Most (10 out of 33) used “physician-assisted death.” This removes the stigma of “suicide,” but it is not entirely accurate, since physicians are rarely present when the patient takes the medication or dies as a result. So their “assistance” is remote. We will return to this question below.

*Hospice Philosophy and Values.* The authors’ analysis of documents identified 22 values specifically invoked by hospice documents. These included relief of pain and suffering, information disclosure, respect of conscientious refusal, compassionate care, non-abandonment, enhancing quality of life, respect for patient choice, respect for patient-physician relationship, and refraining from hastening death. These values were named with almost equal frequency. “Relief of pain and suffering” was explicitly named by 31 of the 33 hospices.

*Dilemmas of Hospice Staff Presence.* Despite their commitment to patient care and non-abandonment, 78% of hospices restrict their staff from being present, as a matter of policy, at time of self-administration of medication and during the time between ingestion and death. Only one hospice saw “supportive presence” even during administration of medication, to be part of their commitment not to abandon their patients.

The most important issue in my view is whether hospices see PAS as part of or complementary to their end-of-life care, or whether they see it as an alternative. Campbell and Black’s research identified four possible positions on this question. They describe the policies of 7 of 33 hospices as “opposition,” e.g., the hospice program “shall not offer, facilitate, participate in or provide an act that directly or indirectly leads to any person participating in the process of providing or facilitation.”

Eleven other hospices had what the authors describe as a “non-participation” approach, which they break down further into “procedural non-participation” (unwillingness to be part of the legal procedures leading to assisted suicide); and clinical non-participation (unwillingness to be part of the act of ingesting the medication).

A third category is “non-interference,” which means that assistance in dying is “a matter between patient and physician,” which places it outside of the scope of hospice care. This might be a variation on a “don’t ask, don’t tell” policy.

Finally, some hospices base their policies on the value of “respect for patient choice.” This means that they see providing information about all options, even self-administered medication, to be part of their mission to inform the patient even if they will not participate in or enable the act in any way.

Campbell and Black agree with Bruce Jennings that these variations demonstrate the “dynamics of an essential ethical tension”.<sup>4</sup> They (and I) also agree with Jennings’ observation that physician assisted suicide represents a “defining moral choice” for hospice identity. They recommend that hospices must attend to this important issue by means of “reflection and discussion on the meanings and purposes of hospice care and understanding of fidelity and integrity to hospice values. The tool they present is designed to facilitate that reflection.

### **Ethical Issues**

Campbell and Black describe their work as “reportorial, interpretative, thematic and coherentist.” They do not set out to provide a thorough moral analysis of various positions they report. I cannot do that in this brief article, either, but I would like to highlight what I see as some important ethical issues

raised by their investigation. These issues could, along with Campbell and Black's discernment tool, help hospices clarify their assumptions and their policies.

### *Terminology*

Words matter. It is clear from the variety of terms used to describe the act by which a patient ends his or her life that there is some willingness to adopt different terminology in order to remove the stigma or actually redefine the act in a more socially or morally acceptable way.<sup>5</sup> While "aid-in-dying," "self-administration of a lethal medication" and "hastening death" all sound more neutral, I believe that they obscure the fact that what is at issue is a patient's conscious, free decision to end her own life. We have always considered this to be suicide, and we have always maintained that it is immoral to the extent that it is a free, conscious act. We no longer deny suicide victims a funeral or burial in consecrated ground. This is an acknowledgement that we can never know the patient's state of mind at the time of the suicide. There is always the chance that the patient's moral freedom was limited by illness, depression or some other factor. But we still see suicide as objectively immoral.

The role of the physician is also at issue. Some hospices have opted for "self-administration" rather than "physician assisted" language, which appears to put the moral burden on the patient rather than the physician. Although the physician's "assistance" is remote, it is nonetheless real and formal, because the patient could not end his own life without the physician's active participation. Even if the physician is not physically present when the patient ingests the medication, he shares in the patient's intention to some extent. I believe we should keep the language of "physician assisted" to make it clear that the physician is not just a vending machine, but rather an informed moral agent who must accept some of the

responsibility for the patient's death. I also wonder whether it is ethical for a physician to supply the means for such an act, and then fail to be present when it takes place.

### *Killing, Letting Die and (unintentionally) Hastening Death*

Another gray area is whether there is a meaningful moral difference between unintentionally hastening death by increasing doses of painkillers and actually taking steps to end a patient's life. As long as we have known that morphine can suppress respiration and possibly hasten death, we have analyzed it in terms of the principle of double effect. The intended effect is the relief of pain. We do not want or intend to hasten the death of the patient, but we can foresee that this might occur. In my view we should take care to assure that "hastening death" as an unintended side effect does not become confused with intentional attempts to bring about the patient's death.

### *Moral Complicity*

Most of the policies analyzed by Campbell and White indicate sensitivity to the fact that the presence or participation of staff members in assisted suicide may involve unacceptable moral complicity or create moral distress for the caregiver. This is true for individual caregivers as well as for the hospice itself. Catholic hospices should therefore make it clear in their policies and in patient and family orientation that patients may not ingest medication while in a hospice facility. If they choose this route, they place themselves outside of the mission of the hospice and must check out to return home.

Moral complicity extends to statements about "respect for patient choice." How far can a staff member go in telling a patient about an option for assisted suicide without promoting or appearing to promote it? Perhaps it is acceptable to mention assisted suicide

only if the idea is introduced to make it clear that it is not part of hospice care.

### *Integrity of the Hospice Mission*

Hospices have been struggling for greater acceptance for many years. It would be a shame if now, when hospice is becoming better known and more widely accepted, hospices obscure or confuse their missions by ambivalence about assisted suicide.

Acknowledging the possibility of assisted suicide in a hospice would be an admission that we cannot help you die well, but we can help you die.

We believe that death is the doorway to the ultimate purpose for which God created us. It is, as one author described it, an “adventure in Christ.”<sup>6</sup> At least for Catholic hospices, it should be crystal clear that hospice is an effective *alternative* to assisted suicide, one that makes assisted suicide unnecessary. In our view, hospice is a clinical, psychological, social and spiritual program to help patients prepare for death and to achieve a “happy death,” one free from anxiety and pain and which occurs in the midst of a caring community.<sup>7</sup>

<sup>1</sup> Courtney S. Campbell and Margaret A. Black, “Dignity, Death and Dilemmas: A Study of Washington Hospices and Physician Assisted Death.” *J Pain and Symptom Mgmt.* 49(January 2014): 137-153.

<http://dx.doi.org/10.1016/j.jpainsymman.2013.02.024>.

<sup>2</sup> A summary of the status of “death with dignity” acts in all states, plus summaries of legislation in states that have approved it, is available at

<http://euthanasia.procon.org/view.resource.php?resourceID=000132> (accessed 3/29/2016).

<sup>3</sup> *Ibid.*, 139.

<sup>4</sup> Bruce Jennings, “Unreconcilable Differences? *Hastings Center Report* 41(2011): 4-5.

<sup>5</sup> Campbell and Black make a similar claim when they note their conviction that “how the practice [of physician assisted suicide] is perceived and interpreted, as displayed by the language phrasing, is not value free but presupposes

value assumptions that inescapably influence moral assessments and policy positions...” (141).

<sup>6</sup> Benedict Ashley, Jean deBlois, Kevin O’Rourke, *Health Care Ethics: A Theological Analysis*, 5<sup>th</sup> edition (Washington: Georgetown University Press, 2006): 166.

<sup>7</sup> See Philippe Aries, *The Hour of Our Death* (Oxford, 1981) in which he discusses the persistence of the idea of a “tame death,” which is close and familiar. He contrasts this with the “wild death” that is isolated and out of control. Daniel Sulmasy makes a similar distinction in his book *The Rebirth of the Clinic*, in which he cites the unintended effects of clinical medicine after the Enlightenment.

## Placement of Migrant Children with Human Traffickers

In February, a *Washington Post* editorial argued that the Office of Refugee Resettlement, part of the U.S. Department of Health and Human Services, needs to clarify who is responsible for monitoring the welfare of unaccompanied migrant children while they await their immigration hearings. A Senate report confirmed that at least six children were placed by HHS in a trafficking ring at an egg farm in Trillium, Ohio. The same report documented 13 other cases of migrant children being placed in trafficking situations with 15 more cases showing some evidence of trafficking. HHS has strengthened its background-check process but states they are not accountable for the care of the children once they are placed in a home. The HHS believes the care and safety of the minors in placement is the responsibility of state and local child protection agencies. “Handing Minors Over to Human Traffickers”, The Editorial Board, *Washington Post*, February 6, 2016  
[https://www.washingtonpost.com/opinions/handling-minors-over-to-human-traffickers/2016/02/06/c74812f4-c938-11e5-88ff-e2d1b4289c2f\\_story.html](https://www.washingtonpost.com/opinions/handling-minors-over-to-human-traffickers/2016/02/06/c74812f4-c938-11e5-88ff-e2d1b4289c2f_story.html)

## Statistics on Human Trafficking

An article, published by the *Catholic News Agency*, reported the following statistics from the U.S. Department of Justice: 83 percent of victims in confirmed sex trafficking incidents are U.S. citizens; 67 percent of labor trafficking victims are undocumented immigrants; and 28 percent of labor trafficking victims are documented immigrants. Tina Frudnt, a survivor of human trafficking and founder of the survivor-run program, Courtney’s House, warns that victims are usually 11 to 14 years old. Traffickers approach young children as friends and slowly manipulate them into dangerous situations.

For victims of labor trafficking, it is easily hidden as the jobs appear very similar to a common workplace situations in the beginning. Slowly, working conditions worsen and mistreatment becomes the norm. Catholic Relief Services and the U.S. Conference of Catholic Bishops have both partnered with the U.S. State Department to protect victims and prevent trafficking. “What You Think You Know about Human Trafficking Is Probably Wrong”, *Catholic News Agency*, February 11, 2016  
<http://www.catholicnewsagency.com/news/what-you-think-you-know-about-human-trafficking-is-probably-wrong-55418/>

## Lower Drug Prices Found Through Online Tools

Across zip codes and pharmacies, prices of generic drugs can vary vastly, but without access to published prices consumers do not know if they are receiving a fair price. Two websites, GoodRx and Blink Health, are making prescription drug prices available to the public. These sites are offering prices that are usually only available to insurers. GoodRx shows prices for generic drugs at various pharmacies and connects consumers to coupons. Blink Health not only shares prices but allows patients to buy online and pick up at local pharmacies. This is beneficial to the uninsured who are paying higher prices and those who have insurance plans that require a flat fee for prescription drugs, usually \$10. Purchases made through these sites do not include name brand drugs and usually do not count toward insurance deductibles. Express Scripts, the nation’s largest drug-benefits manager, recognizes that these sites could help some consumers save money but believes most consumers save more using insurance. “New Online Tools Offer Path to Lower Drug Prices”, Katie Thomas, *The New York Times*, February 9, 2016  
[http://www.nytimes.com/2016/02/10/business/taming-drug-prices-by-pulling-back-the-curtain-online.html?\\_r=0](http://www.nytimes.com/2016/02/10/business/taming-drug-prices-by-pulling-back-the-curtain-online.html?_r=0)

## HHS Considering Action on Drug Patents to Control High Prices

A recent article on *The Hill* ([www.thehill.com](http://www.thehill.com)) addresses prescription drug prices. In January, 50 House Democrats sent a letter to the HHS urging them to issue guidelines on administrative action surrounding a rule that could lower drug prices. As part of a 1980 law, when federally-funded research was involved in creating a new drug, the HHS can break the patent to lower the price if they rule the drug is not made “available to the public on reasonable terms.” At this time there are not guidelines for when and how this power can be used. “HHS Considering Action on Drug Patents Over High Prices”, Peter Sullivan, *The Hill*, February 10, 2016 <http://thehill.com/policy/healthcare/269003-hhs-considering-action-on-drug-patents-over-high-prices>

## One Health System’s Plan to Lower Health Care Costs

Intermountain Healthcare, a nonprofit health system in Salt Lake City, created a new health plan, SelectHealth Share, which guarantees to hold yearly rate increases to one-third to one-half less than other employers. Intermountain recognizes there are financial risks if patients require a lot of expensive care. Therefore, they are focusing on the most costly patients by creating a special clinic to serve the sickest patients. At this time, the clinic is open to serve 1,000 chronically ill patients but only has 140 enrolled. Intermountain believes the clinic is promising but will not have information to share publically until this summer. Intermountain has also agreed to care for a third of its patients for a fixed amount which requires careful monitoring of patients’ health to keep expenses at a minimum. In order for this to work, Intermountain acknowledges that everyone has to

play their role. Doctors have to agree to use electronic medical records and share outcomes. Employers must offer affordable plans and a health savings account. Employees are required to participate in health risk assessments and health screenings to ensure early detection. “A Novel Plan for Health Care: Cutting Costs, Not Raising Them.” Reed Abelson, *New York Times*, February 17, 2016

<http://www.nytimes.com/2016/02/18/business/a-novel-plan-for-health-care-cutting-costs-not-raising-them.html>

## Are Americans ‘Gaming’ Obamacare?

In a recent *LA Times* column, Michael Hiltzik reported on claims that Americans are “gaming” Obamacare by gaining access to insurance only when they get sick. The HHS recently asked insurers to provide data about high-cost individuals enrolling during special enrollment periods (SEPs). Most insurers provided comments but none of those reviewed by Hiltzik reported empirical data. SEPs can include life events such as marriage, divorce, or birth of a child. Other nontraditional SEPs include becoming a U.S. citizen, moving to a new state, or becoming eligible for subsidies. Hiltzik reports that studies by the Urban Institute and the University of Michigan found a large number SEPs eligible consumers (about 85 percent) do not enroll. Insurance providers want to make SEPs shorter and require more documentation but this may only increase the number of sicker patients using SEPs. If the process is too complicated, consumers who do not need immediate care, such as the young, will not follow through. Only the sickest will complete a difficult process because they have the highest need for health care. “More Signs That ‘Gaming’ By the Sick Is Not a Problem in Obamacare.” Michael Hiltzik, *LA Times*, February 17, 2016

<http://www.latimes.com/business/hiltzik/la-fi-mh->

[gaming-by-sick-americans-is-not-a-problem-in-obamacare-20160217-column.html](#)

## The State of Rural Hospitals: Closing and At-Risk

Health care costs are driving some rural hospitals to close their doors. In a recent article on *Becker's Hospital Review*, Ayla Ellison reports 15 things to know about rural hospital closures. Over 60 rural hospitals closed since 2010 and more than 673 rural hospitals are in danger of closing. Of those in danger, sixty-eight percent are critical access hospitals. It was found that rural hospitals in southern states and facilities in states that have not expanded Medicaid are more vulnerable to closing. States that have extended Medicaid experience a 50 percent drop in care administered to patients without health insurance, according a study from the University of Michigan in Ann Arbor. The closing of hospitals has many different effects on the community. If all 673 rural hospitals were to close, 99,000 healthcare jobs and an estimated \$277 billion would be lost, according to iVantage. "The Rural Hospital Closure Crisis: 15 Key Findings and Trends." Ayla Ellison, *Becker's Hospital Review*, February 11, 2016 <http://www.beckershospitalreview.com/finance/the-rural-hospital-closure-crisis-15-key-findings-and-trends.html>

## Palliative Care Benefits for All Patients

Palliative care became a medical specialty in 2007 and today more than 70 percent of hospitals offer palliative care services. Palliative care focuses on quality of life, emotional and spiritual needs of the patient and caregivers, treatments to ease symptoms and help in documenting a patient's preferences for medical care. Palliative care can be used at any point in the illness without stopping curative treatment. Sometimes palliative care is confused with hospice and thus avoided by patients who could benefit from

its services. Dr. Eric Widera, from U.C.S.F Cancer Center, explains, "We hear this all the time: 'They're not ready for palliative care,' as if it's a stage people have to accept, as opposed to something that should be a routine part of care." Several studies have shown that people who use palliative care services score higher on quality of life measures, are less likely to suffer from depression, spend less time in intensive care units and report greater satisfaction with care. "In Palliative Care, Comfort Is the Top Priority," Paula Span, *New York Times*, February 12, 2016 <http://www.nytimes.com/2016/02/16/health/in-palliative-care-comfort-is-the-top-priority.html>

## Canadian Palliative Care Center Rejects Doctor-Assisted Suicide

Bruyère Continuing Care, a publically funded Catholic health institution and Ottawa's biggest palliative care hospital, will not offer doctor-assisted suicide to eligible patients. The Catholic Health Sponsors of Ontario said doctor-assisted suicide will not be offered in their institutions, "nor will we directly or explicitly refer a patient to receive this same medical procedure." Death with Dignity Canada responded saying "we believe that all publically funded institutions, including Catholic hospitals, hospices and health authorities need to respect Canadians' charter rights for assisted death if the person meets the eligible criteria." Catholic Health Sponsors of Ontario's president and chief executive John Ruetz emphasizes that Ontario's Local Health System Integration Act which "makes it clear that no health care organization will be obligated to provide a health service that is contrary to its religious beliefs." Although the act states that physicians in Ontario are governed by the College of Physicians and Surgeons of Ontario which created a draft of guidelines on doctor-assisted suicide, the draft requires doctors refer patients without delay. As a federal law is expected in early June allowing doctor-

assisted suicide, publically funded Catholic facilities rules concerning doctor-assisted suicide will be challenged.

“Catholic Hospital, the Biggest Palliative Care Centre in Ottawa, Says It Won’t Offer Doctor-Assisted Death.” Elizabeth Payne, *National Post*, March 1, 2016

<http://news.nationalpost.com/news/canada/catholic-hospital-the-biggest-palliative-care-centre-in-ottawa-says-it-wont-offer-doctor-assisted-death>

### Houston Prepares for Zika

As the Zika virus spreads throughout Latin America, some U.S. cities are preparing for its arrival. One such city is Houston, Texas. Pete Hotez, the dean for the National School of Tropical Medicine at Baylor College of Medicine, sees Houston as the perfect breeding ground for the virus. Houston has a steady flow of people arriving from other countries at their major international airport. Houston also has high numbers of mosquitos in the summer which can carry the Zika virus. Lastly, Zika is a disease of poverty.

Less affluent neighborhoods have more trash on the streets which hold standing water and those spots become places for mosquito larvae to thrive. The city, county and state plan to prevent the spread of Zika through careful monitoring at the airport and more frequent trash pickup. The area officials are asking the citizens to help by removing trash that holds standing water and seeking immediate medical attention for any symptoms of the virus. “Houston Prepares Now for Zika’s Potential Arrival This Summer,” Joe Palca, *NPR*, March 21, 2016

<http://www.npr.org/sections/health-shots/2016/03/21/470683503/houston-prepares-now-for-zikas-potential-arrival-this-summer>

*Students from the Saint Louis University School of Law Center for Health Law Studies contributed the following items to this column. Amy N. Sanders, assistant director, supervised the contributions of health law students Ashtyn Kean (JD anticipated 2017) and Merlow Dunham (J.D./M.H.A. anticipated 2019).*

### When Fear Becomes an Unintended Public Health Problem

At a time when health crises are common occurrences in daily headlines, such as the Zika virus in 2016 and the Ebola outbreak in 2014, public health authorities are urged to alert the public, not alarm. This balance is especially needed due to the growing trend in people turning to social media, friends and politicians for health sources, as opposed to more accurately informed medical professionals and public officials. The days of organized press conferences by National Institute of Health and Centers for Disease Control officials seem to be long gone, drowned out by those seeking their five minutes of fame. The Ebola outbreak in 2014 revealed this concerning trend, as tweets, talk show hosts and online commentary dominated the news stream, as opposed to professors, public health officers, physicians and government officials like in earlier years. This trend resulted in widespread public ignorance regarding virus transmission, as medically inaccurate and unproven falsities spread by politicians and otherwise overshadowed scientists’ retorts. These falsities led medical center communication teams to have to “play defense” against those articulating incorrect information in order to quell needless alarm instigated by the media and elsewhere. This article continues to vouch for “measured and precise” messages to the public, like that of World Health Organization Director-General Margaret Chan’s announcement regarding the Zika virus as a “public health emergency,” as well as President Obama’s reassuring message on *CBS This Morning* thereafter.

Doug Levy, *National Public Radio*, Feb. 19, 2016  
<http://www.npr.org/sections/health-shots/2016/02/19/467123373/when-fear-becomes-an-unintended-public-health-problem>

### Many Dislike Health Care System but Are Pleased With Their Own Care

A poll conducted by NPR, the Harvard T.H. Chan School of Public Health, and the Robert Wood Johnson Foundation has indicated that only one third of the American public say their health care is “excellent,” even though the United States has the most advanced health care in the world. Even fewer than that one-third is impressed with the American health care system as a whole. Interestingly, the poll indicated that 80 percent of Americans say they receive “good or excellent” care, but subsequently rate their respective state’s health care system as “fair or poor.” Dr. Georges Benjamin, executive director of the American Public Health Association, opines that this distinction between personal health care satisfaction and system-wide dissatisfaction is an “amazing kind of schizophrenia about our system;” essentially that while the U.S. delivers the best medicine and nursing in the world, our system is “wildly complex and hard to navigate,” thus resulting in personal approval but system-wide disdain. Subsequently, Sarah Dash, vice president for health policy at the Alliance for Health Reform in Washington, D.C., states that health care is designed for the health care system and doctors, not for patient needs and efficiency, as evidenced by repeat tests, lack of results, and multiple doctor visits. These inefficiencies promote system-wide discontent. The poll further indicated that quality of care can be heavily dependant on a patient’s income: “[a]dults with incomes below \$25,000 a year are about three times as likely as higher income people — 34 percent versus 13 percent — to say the health care they personally receive is only fair or poor.” Likewise,

while the Affordable Care Act includes a number of pilot projects aimed at cheaper and improved patient care, little has changed since its implementation. The poll indicates “74 percent of people believe their health care has stayed about the same since the ACA was implemented. And for the minority who've seen a change, about 14 percent say their care is better while 9 percent say it's worse.” Alision Kodjak, *National Public Radio*, Feb. 29, 2016

<http://www.npr.org/sections/health-shots/2016/02/29/468244777/many-dislike-health-care-system-but-are-pleased-with-their-own-care>

### Health Apps May Pose Major Privacy Concerns

New research has begun to suggest that mobile health apps aimed at tracking personal information regarding health, fitness, and specific medical conditions are posing serious privacy concerns. A study published in the *Journal of the American Medical Association* has found that many of these health apps are transmitting sensitive medical information to third parties, aggregators and advertising networks. Such sensitive medical information includes disease status and medication compliance. Researchers from the Illinois Institute of Technology Chicago-Kent College of Law compiled all available Android diabetes apps’ privacy policies and permissions on which to base this study. By installing a random selection of the apps, the researchers determined whether data were transmitted to third parties (any website not directly under the developer’s control). 211 of the apps remained available after six months, and 80 percent of these apps had no privacy policies. Further, not all of the provisions contained in those 41 apps containing privacy policies actually protected privacy. More than 80 percent of those 41 collected user data, almost 50 percent shared data, and only four policies said they would ask for permission from the user to share data. Another study by the same authors, containing an analysis of 65 diabetes apps, indicated that sensitive

information, such as insulin and blood glucose levels, was routinely collected and shared with third parties. As such, the authors of these studies note that these apps' collection and sharing of sensitive health information is not generally prohibited by law, and therefore urge caution for those using them. Ashley Welch, *CBS News*, March 8, 2016

[http://www.cbsnews.com/news/health-apps-may-  
pose-major-privacy-concerns/](http://www.cbsnews.com/news/health-apps-may-pose-major-privacy-concerns/)

### Hacking of Health Care Records Skyrockets

Health care record hacking is up 11,000 percent in the last year alone, and amounts to 100 million records stolen. While most are entirely unaware, roughly one out of every three Americans has had their health care records compromised. Many of these hacked and stolen records appear on the “dark web,” where hackers advertise their records openly. Medical records are a gold mine and provide a lifetime of information, including the patients' name, address, social security number and medical conditions. Unlike credit cards, which sell for \$1-\$3 on the dark web, and social security numbers, which go for \$15 each, health care records, sold at \$60 a piece, cannot be quickly cancelled. Hackers and criminals can use these records to do just about anything, including ordering prescriptions, paying for treatments and surgeries, and filing false tax returns. For instance, John Kuhn, a recent hack victim, was billed \$20,000 for a surgery he never had after a hospital visit for a simple x-ray. Kuhn's medical records were stolen, along with the hospital's hard drive. Kuhn was able to demonstrate to the hospital's billing department that he never received the surgery by showing his lack of a scar on his belly, though other victims are not so lucky. For this reason and more, security officials, and Kuhn himself, advise free credit monitoring, understanding security policies, following good password practice, using email variations and pin codes, and avoiding giving out your social security

number to hospitals and doctor's offices. Tom Costello, *NBC News*, Feb. 13, 2016

[http://www.nbcnews.com/news/us-news/hacking-  
health-care-records-skyrockets-n517686](http://www.nbcnews.com/news/us-news/hacking-health-care-records-skyrockets-n517686)

### The End of Prescriptions as We Know Them in New York

On March 27, New York became the first state to require all prescriptions be created electronically – a requirement that will be backed up with penalties for physicians who fail to comply, including fines and imprisonment. Minnesota has a similar law requiring electronic prescriptions, but does not mandate punishment for non-compliance. The law comes from a 2012 state law known as I-Stop, which was designed to decrease prescription opioid abuse, a problem that has become enormous in New York. According to the State Health Department, there were more controlled-substance prescriptions written from 2013-2014 than there were residents in the state – 27 million versus 20 million. Further, in 2004, there were 341 opioid-related deaths in New York, as compared to 1,227 in 2013. The first major component of I-Stop is an online registry that a physician must check before prescribing a controlled medication, which was implemented in 2013. The second major component is the transition to electronic prescriptions, and is intended to reduce fraud and mistakes caused by misinterpreted handwriting. New York's Attorney General Eric T. Schneiderman helped write the legislation, and states that “[p]aper prescriptions had become a form of criminal currency that could be traded even more easily than the drugs themselves... By moving to a system of e-prescribing, we can curb the incidence of these criminal acts and also reduce errors resulting from misinterpretation of handwriting on good-faith prescriptions.” The shift has not appeared to cause too many difficulties for hospitals and nursing homes to adopt thus far, and even some health care providers

are relieved to be saying goodbye to the prescription pad. Sharon Otterman, *The New York Times*, March 14, 2016

<http://www.nytimes.com/2016/03/15/nyregion/new-york-to-discard-prescription-pads-and-doctors-handwriting-in-digital-shift.html?ref=health>

### **Major Companies Form “Health Transformation Alliance” to Reduce Health Care Costs**

Twenty companies—including IBM, Coca-Cola, and Verizon—formed the “Health Transformation Alliance,” which will share health spending and patient outcomes data in an effort to reduce health care costs. The Alliance covers about four million people and plans to use its data findings to change how the companies contract for employee health care, potentially by forming a purchasing cooperative to negotiate for lower prices with providers that have better outcomes in treating certain sicknesses. The new big-employer initiative was devised by the American Health Policy Institute, a think tank focused on developing employer strategies to provide affordable care to employees and headed by Tevi Troy, a top health official in the George W. Bush administration. While several big employers like Sears Holdings Corp. have experimented with creating their own private health exchanges, some members of the Alliance have been skeptical of such approaches, arguing that they have demonstrated modest savings at best. The formation of the Alliance demonstrates an innovative way that companies can use their collective data and market power in a bid to lessen the financial burden of increasing health care costs. Louise Radnofsky, *The Wall Street Journal*, Feb. 4, 2016 <http://www.wsj.com/articles/companies-form-health-insurance-alliance-1454633281>

### **CMS Publishes the Long-Awaited 60-Day Repayment Final Rule**

Six years after the authorizing statute and four years after the Proposed Rule was issued, CMS has published the long-awaited Final Rule regarding reporting and returning Medicare Part A and B overpayments. Since the inception of section 6402(a) of the Affordable Care Act, there has been confusion among providers, regulators, and courts regarding the requirements and impact of Social Security Act section 1128J(d), which mandates that a person must report and refund a Medicare and Medicaid overpayment within 60 days the overpayment was “identified” or the cost report is due. Confusion centered on the duration of the look-back period and what it means to “identify” an overpayment, which the Final Rule clarifies. The Final Rule officially establishes a 6-year look-back period, as opposed to the 10-year look-back period offered in the Proposed Rule. The 6-year look-back period is not retroactive and is effective March 14, 2016. Also, the Final Rule states that providers have an obligation to exercise “reasonable diligence” through “timely, good faith investigation of credible information,” including both proactive and reactive reviews of Medicare billing. This period of reasonable diligence may take “at most six months from receipt of credible information, absent extraordinary circumstances,” such as complex investigations involving a Stark Law violation. An overpayment is not considered “identified” until the refund amount has been “quantified.” After the timely investigation period, the 60-day clock starts running.

Failure to make reasonable diligence efforts, including not conducting diligence with deliberate speed after receipt of credible information, or failure to otherwise comply with this rule is treated as a violation of the federal False Claims Act. The Final Rule is effective March 14, 2016, is not retroactive, and applies to Medicare Part A and Part B providers and suppliers. No final rule has been published that addresses Medicaid requirements. Torrey Young, Jana Kolarik

Anderson, and Lawrence Vernaglia, *The National Law Review*, Feb. 17, 2016

<http://www.natlawreview.com/article/who-what-and-when-cms-final-60-day-rule>

### **Medicare Experiments with a New Reimbursement System for Drugs to Fight Problematic Incentives**

In the current health care system, Medicare asks that physicians buy the drugs they prescribe to their patients, and Medicare reimburses the physicians the average sales price of the drugs plus a 6 percent bonus to cover their administrative costs. Analysts have determined that this policy creates a potentially problematic incentive for doctors. Medicare announced that it will use the Affordable Care Act to test a new reimbursement system, to see if reducing the financial incentives for prescribing expensive drugs results in different drug prescribing choices. In this sort of randomized experiment, physicians in certain places will receive 2.5 percent of the cost of the drug plus a flat fee to cover administrative costs. The aim of this reimbursement system is to narrow the payment gap between different drugs and determine if new payment incentives can lead to more rational, and perhaps less expensive, prescribing behavior. Over time, the spending and health outcomes for Medicare patients in the places testing the new policy and those who continue with the old policy can be compared for findings. While health care facilities that prescribe both cheap and expensive drugs will likely not experience a huge financial change, such as most community doctors and large hospitals, doctors who tend to pay above-average prices for drugs may see financial struggle, such as small, independent practices. The pharmaceutical industry is concerned that this new policy may direct physicians away from newer drugs, cutting into their sales. If pharmaceutical companies raise the price of drugs, the price increases could financially hurt

physicians because of the time lapse between when prices in the market shift and when the government starts paying the new prices. Margot Sanger-Katz, *TheUpshot*, March 10, 2016

<http://www.nytimes.com/2016/03/10/upshot/medicare-re-tries-an-experiment-to-fight-perverse-incentives.html?ref=policy>

### **Medically Assisted Suicide Permitted in California Starting in June**

The End of Life Option Act will go into effect June 9 in California, allowing physicians to prescribe lethal doses of medication to terminally ill patients who want to hasten their deaths. The California Medical Association has released guidelines for the process, including that two physicians must agree the patient has less than six months to live before prescribing the life-ending medication, and the patient must make two verbal requests at least fifteen days apart and one written request that is signed, dated, and witnessed by two adults within forty-eight hours of self-administering the medication. California is the fifth state to permit this end-of-life option for the terminally ill, joining Vermont, Oregon, Washington, and Montana. Kelly Gooch, *Beckers Hospital Review*, March 11, 2016

<http://www.beckershospitalreview.com/legal-regulatory-issues/california-will-allow-medically-assisted-suicide-starting-in-june-6-things-to-know.html> ; the law can be found at [http://leginfo.legislature.ca.gov/faces/billNavClient.xhtml?bill\\_id=201520162AB15](http://leginfo.legislature.ca.gov/faces/billNavClient.xhtml?bill_id=201520162AB15)

# Health Care Ethics USA

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## ETHICS RESOURCES

### Upcoming Webinars

#### The ERDs and Catholic Long-Term Care Providers

April 12, 2016  
1 - 2 p.m. ET

The *Ethical and Religious Directives for Catholic Health Care Services* offer moral guidance, drawn from the Catholic Church's theological and moral teachings, on various aspects of health care delivery.

In this webinar, Father Charles Bouchard OP, S.T.D., CHA senior director of theology and ethics, will review the ERDs – their purpose, content and their underlying principles. He will also describe how they apply to long-term care and aging services and how the ERDs address these issues.

#### 21st Century Genomic Medicine: What Care and for Whom?

April 20, 2016  
Noon - 1:15 p.m. ET

This presentation will examine advances in genetic research and genomic medicine along with the benefits and questions they pose for health care and society. The program will also examine medical and ethical issues in genetic testing and the impact of trends in genomic editing technology.

The presenter is Kevin T. FitzGerald, S.J., Ph.D., Ph.D., Dr. David Lauler Chair of Catholic Health Care Ethics in the Center for Clinical Bioethics at Georgetown University.



To learn more, go to [chausa.org/calendar](http://chausa.org/calendar)

### Help for End-of-Life Decisions

AVAILABLE IN ENGLISH AND SPANISH

The guides feature frequently-asked-questions to help patients, families, physicians and care givers think about end-of-life decisions and prepare an advance directive. CHA developed the guides in collaboration with theologians, ethicists, physicians and nurses within Catholic health care. In addition to reflecting the perspective of Catholic tradition, the guides are helpful to persons from any religious tradition.



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