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FEATURE ARTICLE

First, Do No Harm: Ethical Questions about Ova Donation and Surrogacy

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A recent article in *The New York Times* drew my attention and reflection. Jane E. Brody, personal health columnist for the newspaper, recounted the story of a promising female graduate student who had donated ova to pay for her education.[1] Completing three donations prior to the age of 29, the woman died of metastatic colon cancer at the age of 31. Her case might have been noted simply as a tragic coincidence were it not for the fact that the donor's mother is a physician who began to research and study the link between egg donation and subsequent cancer.

The daughter, an intelligent and capable young woman, had discussed potential risks with a physician at the time of donation and was assured that there were "no known long-term effects" of the hormone injections needed to hyperstimulate her ovaries for ova retrieval.

Catholic health facilities do not in conscience provide in vitro fertilization nor do we facilitate surrogacy. Still, many offer excellent clinical assistance to couples desiring to become pregnant.[2] Furthermore, perinatal and neonatal units in Catholic hospitals care for mothers who have undergone fertility treatments. Reading the article drew me immediately back to the late 1990s and a small hospital in the rural Midwest where I had worked with the ethics committee and offered consultation services. I well recall a meeting with the CEO, chief nursing officer and an ob/gyn physician. The physician had come for a consult, relating that one of his patients (I will call her Jenny), a twenty-year-old state college student, was pregnant and wanted him to

deliver her baby in the hospital in which she was born. She then confided that she was the surrogate mother for a wealthy couple from New York City who would also be present for the baby's birth.

From a farming family, Jenny wanted to supplement her college expenses through payment for surrogacy. She had noticed an ad in her university's newspaper seeking healthy young women willing to travel to New York, undergo assessment and then hormone injections prior to in vitro fertilization and implantation. Jenny's physician noted wryly that coastal fertility centers sought farm-raised, blond-haired, blue-eyed scholar athletes. Jenny fit the bill. She fully enjoyed visiting New York and meeting her baby's parents and considered the injections and procedure a bothersome but necessary step.

The question the physician asked was, "Could a Catholic hospital deliver this child?" If not, his patient would have to travel over 50 miles from home to a physician and hospital with whom she had no comfort or familiarity. The response of the ethics committee was, "We are here to provide care." Additionally, "We don't ask any woman how she got pregnant." Being pro-life means that we care for both mother and baby. Nonetheless the administration was concerned about the possibility of scandal within the community and set forth clear steps to manage what could be a challenging situation for both the mother and the Catholic hospital.[3]

While Catholic hospitals do not offer in vitro fertilization, there is no doubt that many women who have become pregnant through in vitro procedures deliver their babies in Catholic hospitals. The Society for Assisted Reproductive Technology released data in May 2017 indicating that in the 30 years they have kept data, over one million IVF babies have been born in the U.S. They further indicated that these births are at an all-time high with 65,787 babies born in 2015.[4]

Jenny, like the young woman in Brody's article, had been told that there were "no known long-term effects" of the hormone treatment she received. That statement, as it stands, is factual. But the reason for this is that the United States, unlike other medically advanced countries, does not keep an egg donor registry nor a national

inventory of unanticipated consequences of the procedure.[5] Other nations, notably Great Britain, Australia and New Zealand, recognize that reproductive technologies may raise health challenges for donors, and thus regulate the industry and maintain registries of vital information. Records may later provide offspring with essential information for their own health-care choices. The oversight agencies study statistics to investigate the health of both women and children with a focus on obstetric complications, preterm births, cerebral palsy and cancer. However, these oversight agencies note that more research and follow-up studies are needed.[6]

For a variety of reasons, the U.S. treats these technologies more as a business than as health care.[7] A perusal of ethics literature from the mid-1980s to the mid-1990s reflects the ongoing litigation and subsequent debate that followed the famous "Baby M" case. But these and later lawsuits did not change the general laissez faire approach of the U.S. At a minimum, a governmental oversight agency would provide a more comprehensive database listing adverse outcome for mother and child so that the couples who choose to undergo such treatments have solid medical data upon which to ground their decisions. It would also draw attention to the health issues that assisted reproduction raise for mothers and babies.

In the U.S., instead of engaging in the difficult ethical analysis and deliberation necessary to address this divisive issue, legislators essentially punted decisions to the states. Still, a 2015 study by The Pew Charitable Trusts attests to the fact that states drag their feet at any regulation in this high-tech, high-cost, high-profit industry. "The U.S. is the Wild West of the fertility industry," said Marcy Darnovsky, executive director of the Center for Genetics and Society, in the article. The article also quotes ethicist Arthur Caplan who said the business is lightly regulated because "it touches on two 'third-rail' issues…abortion and also the creation of embryos, which politicians run away from because too many people still disagree about the right to use reproductive technologies, particularly who should pay for them and how much."[8] The problem becomes much more serious from a global perspective. Some countries have strict regulations but others – most notably in Africa and Asia - do not, thus often leaving

poorer women vulnerable to the money and treatment offered by these programs.[9]

Jenny's pregnancy was almost 20 years ago. But after reading Brody's article I have wondered about her. Did she have any aftereffects of hyperstimulation of the ovaries? Has she had any other children? Is she aware of the as-yet-unproven conjecture that some egg donors seem to have a higher than average chance of developing cancer? Does she get regular cancer screenings?

Egg donation and surrogacy centers in the U.S. certainly maintain an informed consent process at least from a legal or compliance perspective. However, as Brody's article so clearly notes, the forms simply state that there are "no known long-term effects" of the hormone injections the woman receives. Surrogacy has been practiced in the U.S. since the 1980s and has grown exponentially since then. This cursory type of informed consent is disingenuous at best.

In addition to informed consent, the medical or scientific expert owes the patient or subject truth-telling – defined as veracity, avoidance of lying, deception, misrepresentation and non-disclosure. Granted, because there is no national U.S. registry, and little solid retrospective research exists, fertility centers would presumably maintain that they are not lying nor even hiding information. The long-term information doesn't exist to provide sufficient scientific truth to the egg donor or surrogate.

Another ethical issue must be raised as well, that of exploitation of the donor.[10] While there are some situations in which a woman volunteers to be a surrogate or donor for purely altruistic reasons (for example, carrying a child for a family member or friend), the more common arrangements are made between wealthier individuals and women whose economic circumstances drive them to provide ova for payment. These arrangements can exacerbate already stark divisions between wealthy and poor people, between persons with white privilege and persons of color, between educated and less educated persons. One commentary used the term "alienated labor" observing that the product (the child) is separated from its producer, thus denying the woman the respect and consideration which should be her due.[11] Interestingly, there is little commentary upon the fact that speaking of

the "product" reduces the child to an object rather than a human subject.[12]

Readers of HCEUSA might well ask, "But Catholic facilities do not perform IVF, nor offer surrogacy or egg donation. What can we do about this ongoing situation?" Catholic facilities, with their long commitment to state-of-the-art maternal and child care have a great deal to offer to a national dialogue through physician practice groups and membership in professional organizations. Advocacy for the vulnerable[13] remains an integral part of what it means to be a Catholic institution. Working through long-held existing relationships, health care leaders and their associations can promote national standards and registries so that scientists may glean necessary information to provide robust informed consent to any woman who is considering or has donated ova.

St. John Paul II urged the faithful to engage at the crossroads of present day society, participating in what in Greek culture was called the Areopagus, where contemporary thought leaders respectfully dialogue and debate about culture, science, human life, the economy and politics.[14] Because Catholic facilities do not provide in vitro fertilization and egg donation is not sufficient reason to step aside from the ethical debate and advocacy for vulnerable women and their children who are drawn into the international reproductive technology industry. As Martha Nussbaum says in her column, "What happens to children is my business, and your business, and the business of every citizen. But what happens to the women who bear them is our business, too." [15]

Physicians and scientists commit themselves to "above all, do no harm."[16] Application of this maxim must extend beyond consideration of the immediate harm to patient or subject to the long-term effects of a treatment or procedure. The United States can and must recognize that reproductive technologies are moral, human life issues, not mere business or legal contracts. Those engaged in Catholic health care can and must work to move this process forward toward far greater responsibility and accountability.

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[1] Jane E. Brody, "Are There Long-Term Risks to Egg Donors?" *New York Times*, July 10, 2017.

[2] The rationale for policies in Catholic facilities regarding in vitro is clearly laid out in the USCCB document *The Ethical and Religious Directives for Catholic Health Services* in Part Four "Issues in Care for the Beginning of Life," as well as in the recently published New Charter for Health Care Workers, especially in Part 1, "Procreating". Because of these long-standing commitments, this article does not address these accepted beliefs and practices, but instead looks to further reasons for concern about such practices in the broader medical community.

[3] In this case, of course, we did know the circumstances of the pregnancy; but we still would not have turned a patient away. We did consult with the bishop's health care liaison as Part Six of the ERDs requires (see Directive 67).

[4] "Thirty Years of Assisted Reproductive Technology Data Collection in the USA," Society for Assisted Reproductive Technology, May 1, 2017. Online report.

[5] For a review of surrogacy outcomes (from 1999 to 2013), see: Perkins, Boult, Jamieson and Kissin, "Trends and Outcomes of Gestational Surrogacy in the United States," *Fertility and Sterility*, August 2016. The authors conducted their research from the Centers for Disease Control and Prevention, Atlanta, GA. Their review focused on surrogacy, not on egg donation.

[6] See: P. Doyle. "The UK Human Fertilisation and Embryology Authority. How It Has Contributed to the Evaluation of Assisted Reproduction Technology," *Int J Technol Assess Health Care*, 1999 Winter, 15. Likewise, Australia and New Zealand Assisted Reproduction Database (ANZARD). Neither article directly indicated long-term follow through for women who had undergone hyper-stimulation of the ovaries. Nor was the connection between this stimulation and cancer mentioned as part of these database reviews.

[7] See: L. Frith and E. Blyth. "Assisted Reproductive Technology in the USA: Is More Regulation Needed?" *Reproductive Biomed Online*. October 29, 2014.

[8] Michael Ollove. "States Not Eager to Regulate Fertility Industry," *The Pew Charitable Trusts, Stateline,* March 18, 2015. http://www.pewtrusts.org/en/research-and-analysis/blogs/stateline/2015/3/18/states-not-eager-to-regulate-fertility-industry.

[9] See: Peter F. Omonzejele. "The Ethics of Commercial Surrogate Mothering: A Response to Casey Humbyrd," *Human Reproductive and Genetic Ethics*. 17:1 (2011), as well as the editorial in *America*, "Persons, Not Products." October 20, 2016.

[10] Von Hagel and Mansbach. "The Regulation of Exploitation," *International Feminist Journal of Politics*. 18:2 (2015); Jeffrey Kirby. "Transnational Gestational Surrogacy: Does It Have to Be Exploitative?" *The American Journal of Bioethics.* 14:5 (2014).

[11] Anton van Niekerk and Liezl van Zyl. "The Ethics of Surrogacy: Women's Reproductive Labor," *Journal of Medical Ethics,* 1995:346.

[12] Martha Musick Nussbaum expands on this concern in a recent article, "Surrogacy Laws Cruelly Treat Children as Commodities," NCR Online, October 7, 2017, https://www.ncronline.org/news/opinion/surrogacy-laws-cruelly-treat-children-commodities.

[13] USCCB. *The Ethical and Religious Directives for Catholic Health Care Services*. See Part One, Introduction and Directive 3.

[14] John Paul II. *Redemptoris Missio*. December 7, 1990. #37.

[15] Nussbaum, "Surrogacy Laws."

[16] This phrase, while not found in the ancient text of the Hippocratic Oath, has become central to medical education. It is attributed to the 19th century surgeon, Thomas Inman. See: Daniel K. Sokol. "First, Do No Harm Revisited," *British Medical Journal,* 20, September 2014.

FEATURE ARTICLE

Ethical and Cultural Issues in Genital Cutting and Strategic Suggestions for Reduction

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In April 2017, a physician in Detroit, Michigan was charged with performing female genital mutilation/cutting (FGM/C) on girls aged six to eight. A few weeks later, another physician and his wife were also indicted for participating in or facilitating the procedures. At least two young girls had been transported across state lines to a clinic in Eastern Michigan where the procedure occurred, bringing this case under federal jurisdiction and leading to the indictment of the accused by the Federal Bureau of Investigation.[1]

As the most recent, or perhaps the only, case to be brought under federal law, it brings renewed attention to the issue of FGM/C in the United States. FGM/C, is defined as circumcision, excision, or infibulation of the labia majora, labia minora, or clitoris.[2] Since

1996, FGM/C performed on minors has been considered illegal in the U.S. and is punishable by fines and imprisonment of up to five years.[2] In 2013, "vacation cutting" or transporting a girl to a country outside the U.S. to undergo the procedure was also outlawed. Additionally, state-level legislation, with even harsher penalties in some cases, has been introduced in 23 states.[3]

Adding to the already complex legislative landscape, laws regarding FGM/C may overlap with child abuse laws, depending on the state. As a result, there is variation among the states in what is considered "child abuse," and what is considered culturally excusable medical treatment of children.[3] Such variation in state-level policies makes for unclear guidelines and obligations for mandated reporters, including physicians.

The Catholic Moral Tradition and FGM/C

Catholic moral theology considers FGM/C to be non-therapeutic surgery that violates the principle of totality. It is therefore morally equivalent to mutilation. This principle is stated clearly in the *Catechism* (#2297), as well as in the 1995 edition of the *Charter for Health Care Workers* where it says, … [surgical] interventions are acceptable "for the restoration of the person to health" (#66). Elsewhere, the document quotes Pius XII regarding the principle of totality: "It is not lawful to sacrifice to the whole, by mutilating it, modifying it or removing it, a part which is not pathologically related to the whole" (note #144). This principle is reiterated in *the New Charter for Health Care Workers* (2017), especially in #88 and #89.

There are also serious ethical questions about the ability of young women to understand or consent to the procedures involved in FGM/C. Informed consent is one of the most basic principles in health care ethics; procedures performed without it – or without the informed consent of parents or guardians for minors – are serious violations of basic ethics.

More recently, Pope Francis has made explicit reference to FGM/C. On February 1, 2015, in an address that was part of a meeting on women's issues hosted by the Vatican's Council for Culture, he associated the practice with violence against women: "The many

forms of slavery, the commercialization, and mutilation of bodies of women call out to us to be committed to defeat these types of degradation that reduce them to mere objects that are bought and sold," he said. "Although it is a symbol of life, the female body is unfortunately not rarely attacked and disfigured, even by those who should be its protector and life companion."[4]

There are also local efforts to end FGM. In Kenya, the church has established a child education and Rescue Centre in Suguta Mar Parish premises, located 42 kilometres away from Samburu County headquarters where they provide shelter for girls who leave home to avoid FGM.[5]

Elsewhere in Kenya, Sr. Ephigenia Gachiri has tried to replace cutting with an alternative "coming of age" ceremony.[6] Efforts in the United States, such as those sponsored by the Diocese of Rochester, New York (described elsewhere in this article) are aimed at recent immigrants in the U.S. who might still be at risk for FGM.

FGM/C in the Clinic: A Complex Legal and Ethical Landscape

Regarding FGM/C, physician behavior and decision-making in the clinic are a delicate balance of legal obligations, professional guidelines and medical ethics. Legal obligations are often unclear, and, in practice, provide little in the way of how to provide care that is in the best interest of the up to 507,000 U.S. women and girls that have either undergone FGM/C or are at risk.[3]

Guidelines from The American Academy of Family Physicians (AAFP) that pertain to FGM/C are consistent with U.S. federal law. They encourage physicians to provide the patient and family with "culturally sensitive counseling and education", as well as referral to social support groups, to discourage them from carrying out the procedure.[7] While the AAFP's policy reflects consideration for the sociocultural context of patients and the cultural aspects of FGM/C—a consideration not present in most legislation—these professional guidelines alone do not go far enough to address the complex ethical

challenges that an increasing number of physicians face when treating FGM/C survivors and at-risk populations.

The U.S. has a growing immigrant and refugee population, with approximately 39,000 refugees arriving between October 2016 and March 2017 alone.[8] Socioeconomic status, lack of insurance coverage, language and cultural barriers, ability to navigate the health care system, and immigration status can contribute to this population's experience of poor access to quality health care.[9] Although not a risk exclusive to women and girls in immigrant and refugee communities, FGM/C is viewed as a cultural, religious, and/or social tradition in some of the communities from which these populations have emigrated. For communities of newcomers that already have difficulty in accessing health care and in receiving quality care (i.e., reproductive and maternal care[10]), policies and practices that seek to build trust in the clinic are urgently needed.

Policies on FGM/C in the U.S. are often seen through the lens of human rights, viewing the practice as gender-based violence that is an affront to women and girls, and, hence, as a practice that needs to be eliminated. At the core of these policies, is the intent to reduce harm and to respect the value and dignity of affected women and girls. Indeed, the AAFP guidelines and those from other medical and professional organizations are informed by these legal and ethical principles. In the clinic, however, these criminalizing policies are not easy to implement.

Ethical Considerations

Both policymakers and physicians face several ethical questions and challenges when it comes to FGM/C in the clinic. The first is whether FGM/C can ever be considered a legitimate, non-therapeutic, surgical procedure. Here, it is worthwhile to consider the risks and potential complications associated with the practice, namely: short-term (e.g., infection, sepsis, hemorrhage) and long-term (cysts, recurrent infections, labor complications) physical, mental (e.g., PTSD, trauma)[11], and social risks (exclusion and marginalization).[12] These significant risks make FGM/C distinct from and potentially

more harmful than other procedures that are usually considered legitimate, non-therapeutic, surgical procedures, such as body piercings or body ink.

While most in the medical community advocate against performing FGM/C procedures due to their associated complications and the desire to do what is in the best interest of the patient, criminalizing policies may not be the best approach for treating patients who have survived FGM/C, or for preventing the practice.[13] Similar questions about legitimacy and medical risks are being raised in regards to male circumcision – a practice that is currently tolerated both legally and clinically - by some who express concern over respect for autonomy, and a lack of benefits of circumcision.[14] While FGM/C and male circumcision are distinct from one another in many ways, male circumcision may face similar challenges in the future.

Appropriate patient care and effective prevention of FGM/C are contingent upon the ability of policymakers and physicians to navigate these complex ethical and cultural issues. While approaches to addressing FGM/C in communities and in clinics have taken on a variety of forms (such as advocacy groups, community clinics, community organizing and mobilizing, and so on) and guiding principles (diversity, empowerment, trust, etc.), what these efforts have in common is a commitment to meaningful engagement with groups of interest, typically to both assess and meet community needs.

The Need and Rationale for Community/Patient Engagement

Health systems and providers are uniquely positioned to engage in important considerations of the practice of FGM/C. Physicians are tasked with identifying and treating the physical and psychological effects of cutting. In some cases, the physician may be among the first to discover that a woman or girl has been cut—whether recently or not—and is then faced with several questions related to legal obligations and to the ethical care of the patient.

If the physician is legally obligated to report the case, would reporting it be in the best interest of the patient? If the patient is a minor, what might happen to the patient if the parents are imprisoned? Will reporting this case prevent future cases of FGM/C, or will it lead to greater distrust of physicians in the community, and, perhaps increased secrecy? How does FGM/C impact a patient's medical care? How do the patient, her family, and her community view FGM/C?

Given the lack of clear legal guidance, insufficient and under-evaluated training for health professionals[15], and the dearth of best practices on how to care for survivors of FGM/C and those at risk, many providers and health systems are currently ill equipped to address these pertinent questions. As a result, there has been a consistent pattern of women with FGM/C receiving inadequate preventive and reproductive care[11], as well as underreporting in the health care sector. There is also a lost opportunity to build partnerships and trust with communities that practice cutting.

While, indeed, the practice of FGM/C has harmful consequences – physical, mental, and social—the practice derives meaning from its cultural, religious, and/or social origins. If prevention attempts are to be effective, efforts must be made to understand these sources and how each patient's sociocultural context informs their conceptualizations of the harms, and purported benefits, of FGM/C. Community engagement offers the opportunity to understand sociocultural contexts, as well as values and motives, that may be encouraging the continued practice of FGM/C.

Key Elements of Effective Community Engagement

In the U.S. and other countries with growing immigrant and refugee populations, such as the UK and Canada, organizations and clinics are engaging with these communities in a variety of ways to reduce health disparities, improve health outcomes, and address unique health needs. A brief review of these diverse engagement efforts, as well as published resources on community engagement, reveal some key characteristics of effective approaches both in the clinic and within communities. The elements identified in these

ongoing programs, and in the literature, fall into three main categories: communication and dialogue, work within the health sector, and sustainable partnerships (see Table 1).

Table 1. Elements of Effective Community Engagement. Based on a brief review of ongoing community engagement efforts to address health disparities in U.S. refugee and immigrant communities (and in some cases, FGM/C directly), as well as published resources on community engagement from the U.S. and other receiving countries (UK, Canada).[16,17,18,19,20,22,23,24,25]

COMMUNICATION & DIALOGUE	HEALTH	SUSTAINABLE PARTNERSHIPS
Spaces and platforms for goals, values, needs • Reflection • Listening • Validation	**Training for health professionals** • Types of FGM/C • History, Consequences & Significance of FGM/C in the community	**Integrate community assets & characteristics** • Identify strengths and limitations of your partners • Recognize the community's history of change and relationships
Recognition of context • Avoid judgment, labeling, or blame • Self-awareness • Acknowledgement of potential biases	**Guidelines for Medical Management of FGM/C** • Reflect community needs & women's empowerment • Considers community's values and goals	**Recognize, prioritize, and promote diversity in** • Representation • Participation • Leadership
	Develop & Disseminate Referral Procedures • Clearly defined • System-wide	**Engage and empower communities to take responsibility for change** • Support survivor-led and community-based efforts to change behaviors & attitudes
	Integration with community and legal support networks • Legal counseling services • Community health advisors	**Design and implement comprehensive, flexible programming** • Create "learning systems"
	Implement continual monitoring & evaluation	**Implement concrete feedback and evaluation procedures** • Direct communication between community and service providers
		Require a research component • Identify and understand the causes and consequences of FGM/C within particular communities • Learn from previous and ongoing engagement efforts • Identify areas for improvement • Measure change & validate progress

Examples of Key Elements in Practice

Maricopa County, Arizona: The Refugee Women's Health Clinic

Maricopa County, has a population of 4,242,997 (July 2016 population estimate), of which 14.8% are foreign-born persons.[21] The Refugee Women's Health Clinic (RWHC) was founded in 2008 to provide refugee women in this population with comprehensive, culturally-appropriate care. The clinic sees patients from countries such as Burma, Somalia, Iraq, Burundi, and the Democratic Republic of Congo, some of whom are survivors of, or at risk for, FGM/C.[22] Notably, the stated mission of the clinic is not specifically to eliminate FGM/C in the communities that it serves. Such a statement would jeopardize the relationship it has built with the local refugee communities. Instead, the clinic's stated mission is to address health inequalities and cultural barriers to care.

To achieve its mission, the RWHC has implemented programming focused on empowering and mentoring refugee women. The clinic employs members of the community as patient navigators, "who act as liaisons between the health care system and patients" and offer interpretation services that can facilitate communication and access to appropriate care.[22] Furthermore, the clinic offers educational classes and focus groups on childbirth, newborn care, breast cancer screening and sexual health education. In addition, the RWHC is integrated into a network of local and state agencies that conduct screenings, vaccinations and referrals of new arrivals to the state. Within the network, RWHC specifically supports the improvement of screening and referral for behavioral health.

Program design and clinical practices are informed by ongoing research – specifically, community-based participatory research (CBPR)—carried out by the clinic and its founding director, Crista Johnson-Agbakwu, MD. For example, in partnership with members of the Somali refugee community in Phoenix, Johnson-Agbakwu, et al. (2014),

conducted focus groups and interviews to determine Somali male perspectives on FGM/C and childbirth.[23] This study had important insights for culturally-appropriate reproductive health care for Somali women: for example, male participants expressed awareness and concern over the risks of FGM/C, and attributed poor relationships between women with FGM/C and the health care system to the unfamiliarity of physicians with the practice.

Programming that focuses on empowering and mentoring refugee women and their communities, paired with CBPR aimed at understanding community perspectives on FGM/C and creating dialogue between providers and patients, has contributed to improved, culturally-appropriate reproductive health care at RWHC.

Buffalo, New York: Hope Refugee Drop-in Center

The Hope Refugee Drop-in Center in Buffalo is another noteworthy example of community-based organizing and multidisciplinary collaboration. The center is part of the Jericho Road Community Health Center, and is grounded in a community-based participatory development model that allows its constituents to identify their own needs and goals – medical, financial, educational, or other—and the center then facilitates reaching that goal or fulfilling that need.[24]

Also focused on empowerment and diversity, the center offers services including client-driven case management, transportation, advocacy, education, referrals, and medical services. It also has integrated itself into a community support network that includes ethnic-based community organizations and other service providers (i.e. legal and employment services).[24,25]

Rochester, New York: General Medical Group, Catholic Family Center, and the Monroe Department of Public Health

Rochester is in Monroe County, and is home to approximately 225,000 residents. Each year, Monroe County receives, on average, 800 refugees from countries such as Bhutan, Nepal, Burma, Afghanistan, Iraq, Cuba, and Somalia. The Rochester General Medical Group (RGMG, now part of Rochester Regional Health), in collaboration with the Monroe County Department of Public Health and the Catholic Family Center, stepped up to meet the primary care needs of this population. Services offered through these organizations include: primary care, TB screening, lead testing, referrals, mental health, employment, education, and housing services.[26,27]

Collaboration and identification of each partner's strengths were key to developing a plan that worked to meet the needs of the community. Along the way, flexibility was invaluable, as adjustments had to be made for scheduling, space, and unanticipated challenges. Efforts met with relative success: in a single year, 98% of refugees who arrived in Monroe County were seen within a week of arrival. Additionally, all refugees were vaccinated and put into the care of a primary care physician.[20] This collaboration helps the Catholic Family Center provide a Refugee Resettlement Program that addresses the needs of refugees in a "holistic and culturally appropriate manner, supporting their successful integration, fostering their independence and promoting their earliest possible self-sufficiency."[28]

Ethical Implications for FGM/C: A Framework for Policy and Guideline Development

All projects mentioned in this article emphasize empowerment, diversity, collaboration, and reflection. Developing policies and guidelines for medical management of FGM/C within such a social and ethical framework gives greater consideration to sociocultural context and creates room for more open communication between physicians and patients

who have either undergone FGM/C or who may be at risk. This public engagement framework not only empowers all the principle stakeholders involved in the FGM/C issue to greater self-reflection and self-determination, but it does so in a manner that also fosters greater community level reflection and cultural interaction that can result in an improved understanding of health and health care for all involved. Hence, in the end, not only are basic human rights protected, but everyone in the community benefits from improved health care systems and delivery.

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FROM THE FIELD

Assessing the Ethical Issues in "Safe Injection" Sites

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Drug addiction in the U.S. has now reached crisis proportions. In 2014, 28,000 people died from overdose of illicit drugs such as heroin or prescription opioid painkilling drugs; by 2016 it had risen to 52,000.[1] Deaths from fentanyl have risen 540 percent in three years.[2] The price in ruined families and crime is beyond calculation.

While illegal drug use is by no means limited to cities, there are some urban areas that have high concentrations of illegal drug users which leads to problems in public

safety. One such area is the Tenderloin district in San Francisco. In the spring of 2016, the Partnership for a Healthier Tenderloin was formed. It is a "multi-sector, community-driven collaboration comprised of leaders representing business, education, philanthropy, public health and other government, law enforcement and social service non-profit organizations." Its purpose is to further a spectrum of "harm reduction strategies to address environmental trauma and the health of persons who inject drugs (PWID)". It hopes to develop a clinically supervised safe injection site for PWID.[3] This site will be designed to:

- Reduce the number of drug-related deaths
- Reduce the number of non-fatal overdoses
- Reduce the number of emergency room visits for drug-related sequelae
- Reduce the number of improperly discarded drug paraphernalia
- Reduce the number of PWID who inject in public
- Reduce police interactions for low level crime
- Increase the number of clients who access primary care
- Increase the number of clients who test for HIV
- Increase the number of clients who receive treatment for HIV
- Increase the number of clients who test for Hepatitis C
- Increase the number who receive treatment for Hepatitis C
- Increase the number of safer injection supplies including Naloxone
- Increase the number of clients accessing substance use treatment

One person familiar with the Tenderloin project put it this way: "We had seen innovative clinical settings elsewhere in which people came voluntarily with their own drugs to inject under supervision. In these settings, persons who previously would inject in public under unseemly conditions were treated with respect and dignity. They were given proper, clean supplies and were observed by license professional staff who would intervene if coaching on technique was warranted or there was an unexpected reaction to the drug. This interaction with staff is key to success of these centers. The staff engagement with the drug user can lead to trust and referral for addiction services."

Our purpose in this brief discussion is to analyze the various ethical questions that arise from the establishment of such a site, especially the risk of moral cooperation in illegal drug use. Harm reduction strategies are complex because they involve questions of intention and the difference between morality and public policy.[4] They also raise questions about how an act of cooperation on the part of an individual differs from organizational cooperation by a state or local government, or even a religious institution such as a Catholic hospital.

Assumptions

We will enter this discussion with some working assumptions. First, we assume that there are certain acts that are seriously immoral in themselves (intrinsically evil), apart from intention or circumstances. These are usually acts that are direct violations of justice or human dignity.

Second, we assume that intravenous drug use is objectively intrinsically evil because it is non-therapeutic and causes serious harm to the user. It also encourages illegal drug trade and is linked to the spread of infectious disease.

Third, we assume that it is never morally permissible to share the intention of another who is engaged in or about to undertake one of these intrinsically evil acts. To do so constitutes formal cooperation. However, certain types of *material* cooperation may be acceptable if they are far enough removed from the evil act and if there is a proportionate reason to cooperate with the act in a limited way.

Fourth, we assume that the drug user does not possess full moral freedom. Harmful addictive drug use is always objectively immoral, but there is limited subjective culpability because the addiction limits freedom. This does not let the user off the hook, but in terms of personal responsibility it creates a different situation than that of someone who is able to rationally assess various courses of action and make a free, informed decision.

Proponents argue that the safer injection sites cause a reduction in transmission of infectious disease and result in more addicts seeking treatment.[5] Opponents tend to disagree. For the sake of argument, and to limit our discussion to questions of

cooperation and agency, let us assume that there is a significant drop in infectious disease transmission among addicts, say 35 percent, and let us also assume that treatment centers can document a 15 percent increase in clients who have been using an injection site for at least a month. This latter assumption indicates that users are returning, so that their habits of using are changing.

The "Leper Problem"

Apart from technical questions of moral cooperation which we will examine below, there is a more general problem of fear and repugnance. Drug addiction is a stigma. Addicts frighten us because their behavior is dangerous, risky and unfamiliar. We consider them untouchables as we did AIDS victims in the past. Our fear causes us to see them as geographically, socially, economically or morally distant from us. This is true even on a policy level. Most legislators keep their distance. They are wary of endorsing any program that might be perceived as helping drug abusers so they do not appear to be soft on drugs.

This is understandable on an emotional level, but it is difficult to reconcile with the Gospel call to solidarity. Pope Francis has been particularly outspoken on this by publicly associating with addicts and prisoners, even washing their feet on Holy Thursday. He did so in order to recognize their fundamental human dignity. When he introduced the image of the church as a field hospital, he said:

> The thing the church needs most today is the ability to heal wounds and to warm the hearts of the faithful; it needs nearness, proximity. I see the church as a field hospital after battle. It is useless to ask a seriously injured person if he has high cholesterol and about the level of his blood sugars! You have to heal his wounds. Then we can talk about everything else. Heal the wounds, heal the wounds. ... And you have to start from the ground up.

In June 2017, he spoke to a group of priests about the need to get our hands dirty. A good priest, he said, "stands apart from no one, but is always ready to dirty his hands. A good shepherd doesn't know what gloves

are" (June 3). Later in June he returned to the same theme in his daily mass at Santa Marta, but extended it to the whole church as he said:

> We can't be a community, we can't make peace, and we can't do good without being close to people. Jesus could have just said to the leper, 'You are healed', but instead he reaches out his hand and touches him, becoming 'unclean' himself. This is the mystery of Jesus, the Pope continued, that he takes upon himself our uncleanliness, our sin, our exclusion to become close to us. (June 26)

These general exhortations cannot be taken as the solution to complex issues of cooperation, of course, but they do suggest that some situations are serious enough to risk dirty hands. This article will discuss one of those.

Levels of Agency

Central to the issue of harm reduction programs is the question of moral agency. It matters whether the actor is an individual, a public entity, or a church entity. The conscientious acts of an individual person always aim at virtue and moral perfection, so they must achieve the greatest good possible. Shortcuts are not allowed. To deliberately choose a lesser good when I am aware of and capable of a greater good is the definition of sin.

Organizational choices are different because they are one step removed from the moral choice of an individual. Organizations act not to achieve personal moral perfection but for the good of the organization or for the greater good of society. Organizations can act immorally, of course, but moral responsibility is often not clearly assigned to one person. This is especially relevant when it involves civil authority, as we shall show later.

In addition, acts based on an individual judgment of conscience involve subjective factors such as emotion, persuasion, coercion or mixed motives. For this reason, they are usually judged more leniently than corporate acts which involve legal compliance and public accountability. We expect more lenience and compassion from a confessor than from a judge.

It may be helpful to start with the simplest case of individual cooperation with illicit drug use. Let's say that Ellen has a friend who is addicted to heroin. She is deeply concerned about him and has discussed at length the toll his drug use is taking on him and others. So she proposes a deal: if he agrees to use his drugs only in her house, she will provide a sterile environment and a clean needle. She will also dispose of that needle safely, which her friend has not been doing when he uses on the street. Ellen's intention is not to enable his drug use but to reduce the health hazard to him and others and to keep him in a relatively supervised environment where she might be able to influence him to stop using and seek treatment. Does this constitute illicit cooperation with evil? Or is she changing the circumstances of an action with which she does not agree to make it less dangerous to her friend and to others?

Ellen has involved herself in her friend's addiction, but we believe that her involvement constitutes only mediate material cooperation, which is morally acceptable. She did not add anything essential to the act, because her friend already had a needle. She merely substituted one instrument for another less dangerous one. It seems that the immediate danger provides proportionate reason for her to get as close as she did to an intrinsically evil act.

Morality and Public Policy

Let's take this simplest case of individual action a step further and apply it to a government or other public entity that wants to provide a safer environment for intravenous drugs users. The entity wants to offer a clean space and a clean needle for addicts who procure their own drugs. The agency's intent is to limit the risk of infection, prevent possible overdoses, eliminate hazardous street waste that may cause injury to others, and create an environment that may engender trust and a willingness to discuss rehab.

To analyze this situation, we must distinguish between *morality*, which may be religiously motivated or not, and which is oriented to virtue and personal perfection; and *public policy* (law) which is oriented to public order and the common good. Some actions (e.g., perjury, murder, theft) are both *illegal and immoral*. Other actions are *illegal*

but not necessarily immoral (e.g., driving above the speed limit, conscientious objection to a particular war, civil disobedience). Still others are *immoral but not illegal* (e.g., abortion, adultery, drunkenness, charging unjust interest). These examples show that while morality and legality are similar in some ways, there is not a perfect correspondence. We cannot translate morality directly into public policy.

The purpose of public policy is more limited than the purpose of morality. Therefore, lawmakers may sometimes look beyond individual moral perfection to what will create the conditions for citizens to pursue moral perfection. The noted theologian of religious liberty, John Courtney Murray, said that if we confuse morality with legality, we make a wreckage of them both. This was famously illustrated in the case of prohibition in the United States. Begun as an attempt to instill the virtue of temperance, it failed because it tried to enforce moral goodness by legal interdiction. It not only failed to curb the use of alcohol, but also gave rise to organized crime, bootlegging, a black market for liquor, and health hazards from homemade liquor. The resulting situation was worse than the original problem. This is why we sometimes say "you can't legislate morality." We can create conditions conducive to morality, but in the end, moral perfection is an internal reality that cannot be achieved by coercion or interdiction. I cannot tolerate moral evil in my personal life, but a government can, since its purpose is not the pursuit of personal goodness, but public order. Governments must sometimes "tolerate" moral evil to ensure public order or public health.

Both St. Thomas Aquinas and St. Augustine invoked this distinction between public and private action. They did so with reference to prostitution, which they clearly saw as a moral evil; they also saw it as inevitable, given the human proclivity to sin.[6] So Aquinas asks whether it "belongs to civil law to repress all vice," or to put it another way, should everything that is immoral also be illegal? Even though he spoke in the context of medieval Christendom, where church and state were barely separate, he did recognize that the purpose of civil law was more limited than the purpose of morality and thus that some things we deem immoral could be allowed by law. He says this is true because laws

must be enforceable if they are to be respected and they can only be enforceable if they are respectful of the reality of human weakness. We can't make laws based on the assumption that everyone has achieved virtue.[7] Therefore, he says laws only forbid "the most grievous vices from which the majority are able to abstain"[8] and concludes that civil leaders "rightly tolerate[9] certain evils, lest certain goods be lost or great evils be incurred."

These examples speak to governmental establishment of "safer injection sites." Proposals to do so recognize human frailty and the ways in which addiction impairs human freedom. They do not promote drug use, but they *tolerate* it and try to limit the circumstances under which it takes place to reduce its harmfulness and create circumstances that might generate more freedom for the drug abuser in the hope he or she will seek rehabilitation. The goal here is to protect both the person and the public good from harm by changing the circumstances of intravenous drug use.

A third instance of moral agency might involve a church organization, e.g., a diocesan social service agency or a Catholic hospital, that sets up a safer injection site[10] or establishes one in collaboration with a local or state government. The benefit of church involvement is that some addicts may be more willing to seek help from a church agency if they fear arrest or detainment by police. It might be part of a community benefit program if illegal drug use is identified as a serious community need. It would certainly be a way to demonstrate, as Pope Francis exhorts us and Jesus demonstrates in the Gospel, respect for the dignity of even the most marginalized person.

In principle, such a program would be within the church's mandate to serve the common good and the health and safety of a community. However, there is a significant risk of scandal because the principle of cooperation that might justify such a program is complex and difficult to explain to the public. It could, like programs designed to provide information on prophylactic measures that would prevent the spread of HIV or more recently the Zika virus, give the impression that we condone the acts that are spreading disease. So even though we believe the threat to public health may justify involvement of religious

organizations in harm reduction, they should carefully assess physical proximity, branding (does the program use the Catholic entity's name?), funding and provision of supplies or personnel to avoid the appearance complicity in evil. Exactly what could constitute scandal in this case deserves further specification.

Conclusion

Human nature being what it is, programmatic attempts by civil authorities to address acts that are deeply rooted in human weakness and harmful to the common good appear to be generally acceptable if there is some solid evidence that they are achieving their purpose. We believe that the rapid growth of drug addiction and the spectacular failure of legal interdiction policy suggests that a different strategy is well worth the risk.

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[1] https://www.asam.org/docs/default-source/.../opioid-addiction-disease-facts-figures.pdf

[2]https://www.nytimes.com/interactive/2017/09/02/upshot/fentanyl-drug-overdose-deaths.html

[3] Information about the Partnership comes from a summary from the St. Francis Foundation Urban Solutions Summit held August 31 to September 2, 2016. Provided by Abbie Yant, vice president of mission, advocacy, and community benefit at Saint Francis Hospital in San Francisco. Saint Francis is part of Dignity Health.

[4] See John Kleining, "The Ethics of Harm Reduction: Substance Use & Misuse," Informa Healthcare USA, Inc. 1532-2491 (43:1–16 2008). DOI: 10.1080/10826080701690680. Some other examples of harm reduction as moral justification include arguments mounted in favor of needle exchange programs, nicotine patch use, HPV vaccination for girls, and "snowflake" adoption, i.e., the implantation of unused and unwanted fertilized embryos abandoned in fertility clinics. Seatbelt use is no longer morally or legally controversial, but it too began as a harm reduction strategy.

[5] See Leo Beletsky et al., "The Law and Politics of Safe Injection Facilities in the United States", *Amer Jour Pub Health* (Feb. 1, 2008): 231-237.

[6] Aquinas quotes Augustine who said that if prostitutes were prohibited, "the world would be convulsed with lust" (ST 2-2, q. 10, a 11).

[7] ST, I, q. 96, a.2. "Laws imposed on humans should be in keeping with their condition, for the possibility or faculty of action is due to an interior habit or disposition: since the same thing is not possible to one who has not a virtuous habit as to one who has…" This is an awkward way of saying that you can't get blood from a turnip. A person with very limited virtue or moral goodness cannot appropriate the good behind a particular law in the same way as someone who is wise and prudent.

[8] ST 2-2, q. 10, a 11. Here Aquinas is asking whether the liturgical rites of unbelievers, which were clearly understood to be sinful, should be suppressed by law. They should be tolerated (not approved), he

says, "lest worse evils occur or we deny those who practice the rites the possibility of conversion."

[9] It is important to note that the term toleration here does not refer to the "live and let live", value free acceptance that the term connotes in modern usage. For Aquinas, it had a more specific technical meaning, related to the principle of double effect, of knowing the moral evil involved but stepping back from it for the sake of civil order. It may be the more libertarian understanding of toleration that some opponents of safe injection sites are reacting to.

[10]See for example the case of Bishop Howard Hubbard of the Diocese of Albany, New York. Reported on January 29, 2010. Catholic Charities in the Diocese of Albany set up a van to provide sterile injections to prevent the spread of the HIV virus (http://www.freerepublic.com/focus/f-religion/2440069/). Some found the bishop's decision to be unacceptable. See for example canonlawblog.wordpress.com/2010/02/02/arguments-against/bp-hubbards-authorization-of-needle-programs.

Geisinger Project Begins to Yield Tangible Results from Genetic Data.

MyCode is a project that seeks to find "genetic contribution to illness; to advance knowledge of genomic medicine; and to provide new and improved treatments – and even possibly future cures – for disease." The initial program was developed out of an unusual situation. Through the rise of genetic sequencing, the ability to scan for "superhero genes" – those that actually prevent disease – has been somewhat successful. A few years ago, 13 individuals with gene mutations that protected them from severe illness were discovered through the *Resilience Project*. Unfortunately, the information was completely anonymous – preventing any further contact with the individuals. The anonymity of such an endeavor has been the "Achilles heel of genomic or precision medicine."

This need for patient participation and engagement spurred the creation of the MyCode Community Health Initiative by Geisinger Health System. Unlike previous projects, MyCode has the "permission to re-contact [participants] for further studies and evaluations." After the initial group of 115,000 participants, 148 have been found to hold "gene mutations associated with certain conditions or diseases and were therefore at risk of developing these diseases." With this discovery, and the protocols put in place, MyCode has been able to communicate with the participants directly to provide information and resources. The ability for conversation and interaction allows for the continuation of research into the effects of these "superhero genes." Hopefully, more projects like this will help lead the way on this exciting new research opportunity. *MyCode Community News,* Sept. 2016

Can the U.S. Repair Its Health Care While Keeping Its Innovation Edge?

Some fear that major changes in health care markets and policies will negatively affect American medical innovation. In an Oct. 9 *New York Times* article, authors Aaron E. Carroll and Austin Frakt attempt to clarify this relationship by first establishing America's leading role in health care innovation. "It has more clinical trials than any other country. It has the most Nobel Laureates in physiology or medicine. It has won more patents." They also highlight one publication's ranking of the U.S. as "No. 1 in overall scientific innovation."

After this defense of American ingenuity, the authors examine factors which most likely spur such a creative environment. One is the existence of a "first-class research university system." The existence of so many institutions of higher

education produces researchers who have the knowledge and resources to embark on scientific explorations. Other major factors are America's "robust intellectual property laws and significant public and private investment in research and development." Along with the existence of a "large market in which patients, organizations and government spend a lot on health," authors recognize these factors as most important for the continuation of medical innovation.

The article also maintains that the U.S. can repair its health care while keeping its innovation edge. In fact, the authors argue that changes in payer source should not be our primary concern. With the knowledge of the factors that do promote innovation, we can instead focus on better ways to direct our financial resources. They conclude with a quote from Dr. Ashish Jha, director of the Harvard Global Health Institute, "We have confused the issue of how we pay for care – market-based, Medicare for all, or something else – with how we spur innovation. In doing so, we have made it harder to engage in the far more important debate: how we develop new tests and treatments for our neediest patients in ways that improve lives and don't bankrupt our nation." Aaron E. Carroll and Austin Frakt, *New York Times*: Oct. 9, 2017.
https://www.nytimes.com/2017/10/09/upshot/can-the-us-repair-its-health-care-while-keeping-its-innovation-edge.html

Young Victims of Opioid Crisis Pay High Price

Citing the story of a grandmother raising a 2-year-old grandson dependent on heroin, author Brian MacQuarrie in an Oct. 7 Boston Globe article outlines the tragic effects of the opioid crisis on children across Massachusetts. The child whose name is Mason was "born dependent on heroin…[his] two parents overdosed shortly into his young life." His mother survived, but father did not. Mason was placed into the custody of his grandmother.

This story is not uncommon. In fact, the article states, "since 2013, the average number of children and young adults in state custody has risen 26 percent to more than 9,200 in August." Meanwhile, "petitions to remove children from their homes rose 57 percent statewide from fiscal 2012 to fiscal 2016." Such a large increase has put a massive strain on an already overworked welfare system. To meet the demand, the Massachusetts' Department of Children and Families (DCF) has increased "its staff of social workers by 300" and added "about 140 new foster homes." Even with these increases, "caseloads remain at dangerously high levels in parts of the state, and that some children who should be removed from their homes might slip through the cracks."

The crisis is still in its early phases. Some caution "that the epidemic's long-term impact will not be apparent until today's children become adults." Fortunately, Massachusetts Governor Charlie Baker has made child-welfare reform a "priority of his administration", adding $100 million to the DCF budget. It will take many years and many more millions to see this trend stop. Hopefully, more leaders will make it a priority of their own administrations. Brian MacQuarrie, *The Boston Globe*: Oct. 7, 2017.
https://www.bostonglobe.com/metro/2017/10/07/children-are-lesser-known-victims-opioid-crisis/1D4lkN2kmEzeApqJ1g3BPI/story.html

What I Learned From Organizing, Participating in Boston's 'Amoris Laetitia' Event

Fr. James Keenan, SJ and Cardinal Blase Cupich of Chicago sponsored a seminar, October 5-6 2017, on Pope Francis' apostolic exhortation, *Amoris Laetitia* at Boston College. Notable participants of church leaders and experts included Cardinal Kevin Farrell (prefect of the Dicastery for Laity, Family and Life), Malta Archbishop Charles Scicluna (canonist), and Jesuit Fr. Antonio Spadaro (editor of Civiltà Cattolica).

The schedule included "five panels, each one with three or four presenters" followed by an hour-long discussion. Fr. Keenan shared a few "significant catch phrases for describing the style and content of our seminar." The first was from theologian, Lisa Sowle Cahill of Boston College who remarked, "It's so good that the speakers basically chose to describe the contemporary situation in terms of families, instead of marriages." Keenan noted that this shift in focus helped to prevent the common sidetracking of the conversation towards "the politics of marriage."

Another notable moment Keenan noted was a "much repeated claim" that "we have discovered that there are eight chapters to *Amoris Laetitia*." What may seem like an obvious "discovery" attempts to counter the general focus by the public and church leaders on "footnote 351 that mentions the 'help of the sacraments' for divorced and remarried Catholics…" The recognition and general attention on the whole document allowed the participants to gain "a profound appreciation of the challenges felt by families in the United States." Anyone who has had the opportunity to read the document in its entirety will discover the depth of connection Pope Francis has with the difficulties facing many in the church. By responding to the needs of the family, Pope Francis has called us all to witness to "the church that Francis is inviting us to be." A future publication synthesizing the conversations will be published by Paulist Press. James Keenan, *The National Catholic Reporter*: Oct.

9, 2017.

https://www.ncronline.org/news/opinion/what-i-learned-organizing-participating-bostons-amoris-laetitia-event

Artworks that Teach Faithful How to Die Well

Bowdoin College Museum of Art is showcasing works from around 1500 C.E. What is unique about these pieces is their genre, "memento mori." Some may remember hearing this term in a theology course. It is a "Latin admonition to remember that everyone must die." One piece on display includes "two pages from the 1466 German book *Ars Moriendi* ('The Art of Dying Well') which depict a dying man surrounded by angels and demons. The figures attempt to persuade the man from willing all his possessions to his family, and instead to give some to the church and to charity.

Barbara Boehm, senior curator for the Met Cloisters, states "the best memento mori images stop us in our tracks…and cause us to think about what we are doing with our lives, what kind of legacy we will leave." These images, statues, and manuscripts attempt to "illustrate moral values." However, they "cannot be considered wholly outside theology." By highlighting this exhibition, the author of this article wants to clear some misunderstandings about the memento mori tradition, and the theological debates going on during the 16th century. It is an interesting take on the relationship between expressions of art and the public conversation at the time of its creation. Menachem Wecker, *The National Catholic Reporter*: Oct. 10, 2017.

https://www.ncronline.org/news/media/artworks-teach-faithful-how-die-well

STAT List: These 10 Cities Had the Biggest Jumps in Hospital Jobs

Data from the U.S. Census Bureau and Bureau of Labor Statistics from July 2007 to July 2017 examine gains in hospital employees among the top 100 largest metropolitan areas. The top five cities with most gains in hospital employees are: New Orleans at 78 percent; Boise, Idaho at 72 percent; Austin, Texas at 51 percent; Columbus, Ohio at 51 percent; and Bakersfield, California at 49 percent. This rise in health care fields has been "a main driver of employment gains since the Great Recession." However, "there's a risk too: If the country ever actually tries to control health care costs, it won't be able to support as many jobs in the industry." Andrew Joseph, *STAT News:* Oct. 11, 2017. https://www.statnews.com/2017/10/11/10-cities-hospital-jobs-jump/

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 2018) and Merlow Dunham (J.D./MHA anticipated 2019).

Appeal of Medicare Payment Rule Splits Circuits and Benefits Hospitals

The U.S. Court of Appeals for the District of Columbia Circuit 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, 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. If the ruling were to stay, it would potentially eliminate some of PPRB's appeals backlog as well as increase provider appeals within D.C. federal court. 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

The 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 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 18 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, *The Washington Post*, July 20, 2017 http://wapo.st/2gNrtqr?tid=ss_mail&utm_term=.a436ea15b94f

E-Cigarette Regulation Delayed, FDA 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 remains suspect of e-cigarette flavors aimed at children, such as Tutti Frutti and Banana Mash, and will consider regulation. 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, for which the former called the announcement "an important evolution in the agency's approach to

regulating tobacco." 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 $579 as the average medical debt in collections. 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, both 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 14 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, including 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 (2891 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 54 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 66 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 confirms 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*

THE 2018 HASTINGS CENTER CUNNIFF-DIXON PHYSICIAN AWARDS

2018 NOMINATION CALL

Suggest Your Nominees for the 2018 Awards

The Hastings Center Cunniff-Dixon Physician Awards are presented to recognize and support excellence in care near the end of life.

Prizes in the amount of $25,000 will be awarded to a senior physician (20+ years in practice) and $25,000 to a mid-career physician (8-19 years in practice) who have demonstrated an exemplary commitment to patients near the end of life through their doctoring, research, and/or service to their community.

Three additional awards in the amount of $15,000 each will go to early-career physicians (0-7 years) who have already demonstrated exemplary efforts with patients near the end of life.

Nominations for 2018 are due by December 31, 2017

More information can be found at

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