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# Health Care Ethics USA

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### From the Field

FEATURE ARTICLE

# Disparity as Indicator Species

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In Richmond, Virginia, if a person is born and lives one's entire life in Gilpin Court, one of many public housing developments in the city where there has long been high poverty and residential concentration, one's life expectancy is 64 years. By contrast, if a person is born and lives one's entire life in Glen Allen, a suburb of Richmond with considerably less poverty and residential concentration, one's life expectancy is 82 years.[1] According to the Robert Wood Johnson Foundation, Richmond's disparate life expectancy picture is not unlike many American cities.[2]

Nationally, in the diagnosis and treatment of type II diabetes, African Americans are significantly less likely than whites to see a doctor and to have a regular source of care, and are more likely to visit an emergency department for ongoing treatment of type II diabetes.[3] African Americans are diagnosed with asthma at a 28% higher rate than whites.[4] Hispanics and African Americans are disproportionately affected by HIV. The HIV infection rate for Hispanics is three times that of whites while the infection rate in African Americans is eight times that of whites.[5]

These disparities have long been known and our understanding of why they occur has increased. The Affordable Care Act contains strategies that purportedly help reduce such disparity, and many national organizations such as the American Heart Association and the American Diabetes Association are working to understand and address such disparities. Still, in the current American health care system reform movement, one in which a community wellness approach to health care delivery is taking priority over the failed practice of episodic care, a simple question arises: what will successful transformation look like? In other words, what needs to be observably different in our health system in the future if we are going to achieve community health?

In order to address these questions, let us consider another sort of system for analogy. In wildlife habitats, an "indicator species" is an organism whose relative abundance serves as a marker for the general health of the ecosystem.[6] For biologists, an indicator species is a monitoring tool – as the indicator species goes, so goes the health of the ecosystem. There are positive and negative indicator species. A spotted owl is an indicator of a healthy old-growth timber habitat. Presence of river otters indicates that a wetland is clean and thriving. Algal blooms indicate the hazardous presence of excessive phosphorous, as when rain water run-off contains excessive fertilizer. Indicator species abound.

Recent scholarship in the conflict resolution field provides another helpful lens. The philosophical approach to health reform has loosely followed a couple of strategies from a conflict resolution perspective. Our public officials, private industry and health care systems' leadership have chosen, with varying results, to tackle a series of specific points of disagreement about reform standards and requirements seeking *resolution*. Staged implementation of meaningful use standards and negotiations of mandated employer coverage are two examples.[7] Over more than two decades, they have also acknowledged the complexity of reform and *engaged* in ongoing dialogue to further understand interests and needs of many stakeholders, including patients, systems, insurers and government entities. Both of the aforementioned approaches might achieve improvements, but neither, alone, acknowledges the necessity of right relationships in health care delivery. For this to occur, our nation must utilize both engagement and resolution techniques and go beyond those methodologies to achieve *transformation*.[8] Many talk about transformation, but few understand what that effort involves in terms of the health care relationship that necessarily includes those who deliver, receive, fund and oversee health care services.

Assuming that achieving community wellness, not simply the absence of certain diseases, is the ultimate goal of health reform[9], and recognizing that there are many ways to measure success in reform, we argue that neither ongoing engagement nor resolution of specific problems in American health care delivery will ultimately achieve community wellness without transformation. We also argue that *disparity* serves as a leading negative "indicator species" for our health care delivery system. Persistent health care disparities, assuming the structural reform underway, would indicate that we have not truly achieved a necessary transformation – that we are still in conflict.

For the purposes of this work, we use the notion of disparity in two interrelated ways. Structural disparity, defined as the summation of barriers preventing access and utilization of health-related goods and services, leads to outcomes disparity. Structural disparity is the systemic and institutionalized aspect of disparity whereas outcomes disparity is the experience and practice of inequity and exclusion in health care delivery. We know that structural disparity leads to outcomes disparity because, in cases in which historic structural disparity has been effectively addressed, outcomes improve.[10] Structural disparity might be correlated to a number of factors, including, but not limited to, market-driven and commodity-oriented reimbursement techniques, social inequities and physical isolation, and religious and language barriers. The Affordable Care Act and other legislative actions attempt to reduce structural disparities in hopes of affecting outcomes disparities - measurable gaps in quality and health indicators that exist in virtually every health care arena, as evidenced by a growing body of literature.[11]

Ubiquitous and multidisciplinary presence of outcomes disparities in health care is one aspect that makes disparity a good indicator species. Further evidence is the many successful and failed efforts thus far aimed toward reducing disparities. The Affordable Care Act is perhaps the most comprehensive of all efforts. One stated purpose of passing health care reform is to address disparities in care.[12] This measure is what conflict engagement specialists would refer to as a behavioral remedy.[13] It changes the situation based on compliance with standards of behavior on a societal level. But these experts also know that, for real transformation to take place, resolution must occur on cognitive and emotional levels, as well.[14] These cognitive and emotional components are harder to identify, measure and modulate. So, how can we hope to effect this change? Let us start with historical context and self-reflection.

Although disparities exist in every health system, and not every health-related shortcoming is directly correlated to disparities in care, the United States' socioeconomic picture reflects a prevalence of extremes in poverty that is less apparent in peer nations.[15] In addition, the county by county variation, as measured by U.S. departure from other Organisation for Economic Cooperation and Development (OECD) member countries' median mortality, is most pronounced in poor counties. There is also a similarity among the distribution rates of poverty, obesity, decreased life expectancy and Medicare reimbursement in the United States.[16] While many health care issues that challenge the United States – obesity, cardiovascular disease, addictions – appear to be matters of excess and lifestyle choices, poverty matters because our system is historically market-driven, and poor health accompanies poverty.

The market-driven nature of the American health care system sets us apart from other Western countries. In the aftermath of two World Wars, European countries' infrastructures were decimated and had no means of supporting a medical market place. Post-war Europe was forced to implement new public health models, those in which community health enjoyed priority in order to attend to the most basic health care needs of the whole population. Today, European health delivery systems vary in degrees of socialization and privatization, but the notion that basic health care could be identified as a commodity remains practically nonexistent.

Not so in post war America. In the U.S. there was no consensus that providing basic health care services was either necessary or desirable, and the American public has demonstrated a greater aversion to government programs.[17] Most health care services remained a commodity, and market values took hold. Considering medicine more in the context of rights and duties and less in the context of the free market is new in America, and it doesn't come naturally to us.

If structural and outcomes disparities highlight the roots of our problems in reform, expensive and episodic interventions appear to be the fruits we have born. The medical marketplace promotes disparity and breeds episodic interventions that occur to temporize medical conditions that society has felt compelled to treat but not to prevent. The system has been reactive rather than proactive. We have not empowered wellness or the equitable distribution of limited resources; we have just kept feeding the market.[18] It appears that, as a nation, we now recognize the limitations of the market place in advancing wellness, and the U.S. health system is working toward what we think will be a better model, but it's not simple to do when the structure is essentially set. We are not creating a new system, *tabula rasa*; we are transforming a broken one. The latter maneuver is far more challenging, and it takes a long time to realize.

Our view is that if we transform the structure of health care properly, especially as it relates to the incentives we bring into emerging quality-based reimbursement schemes, then we will see fewer outcome disparities. Moreover, if our public health infrastructure is properly scaled, innovative approaches to community and neighborhood health promotion will prove beneficial in limiting outcome disparities. But we cannot stop there; authentic transformation will also require modelling institutional and leadership behaviors that demonstrate a cognitive and emotional understanding of patient needs. Yes, changing the structure of the system is a primary imperative, but there is more work to be done.

Just as the Fifteenth Amendment to the Constitution did not immediately lead to equal representation for people of color, so the Affordable Care Act will not eliminate disparities by virtue of its existence. There are complex, value-laden factors that also contribute to disparities. After overt structural issues are addressed, our system is still left with stakeholders whose formal and informal training leads them to uphold disparity. Simply put, we must convert the hearts and minds of health care professionals and the American public.

Intergroup attributional biases leading to systematic or institutional discrimination must also be considered.[19] The rugged individual American pioneer spirit can be a great strength and moral voice for personal freedom, but if we allow it to be an institutional justification for retributive justice - the notion that people ultimately should get what they "deserve" - then it can lead to negative attributions in many health care settings. Instead of seeing a person in need in the Emergency Department, one sees a lazy and unmotivated "frequent-flyer." Instead of seeing a person who lacks transportation and a basic understanding of how and when to follow a doctor's recommendations, one sees a non-compliant patient. Instead of seeing patient questions or complaints as an invitation to relationship, one sees a difficult patient. Such attributions can be subtle and we need to understand how they contribute to structural and outcome disparities.

In this attributional paradigm, an observer, perhaps a health care professional, credits a marginalized person's behavior to his character and disposition rather than to her circumstances and place within health care's distorted incentive structure.[20] A more useful paradigm of restorative justice and perception of a person's circumstances as the cause of Emergency Department utilization can, if more deeply routinized within the care system, lead to cognitive and emotional transformation and empower equity and transformation. Attributional errors are already identified as a source of medical errors; it stands to reason that they inhibit the successful transformation of American healthcare.[21]

Institutional biases are compounded by the belief that simply refraining from overtly discriminatory behaviors – especially those behaviors specified in legislation – constitutes an adequate solution to the problem. Yes, there is more work to do on the structure of reform, but leadership and cultural competence must also become a priority if we are to achieve the cognitive and emotional elements necessary for transformation.[22] Operational stakeholders must believe that disparities exist, that they are not merely the result of personal choices, and all ranks must be viscerally invested in eliminating them. The Affordable Care Act does not clearly address how we should manage the cognitive and emotional aspects of disparity, but we won't realize the benefits of reform until we do. Transformation of our health care system will require transformation of our views – about community, justice, responsibility, and freedom. This is an ambitious undertaking. We have seen and should continue to expect challenges to our deeply held personal beliefs and group identities. Observing how well we affect disparity and reflecting on the environmental conditions that have concomitantly changed must be central in transformation because eliminating health care disparities will mean that we have made a real transformation.

It is difficult to overestimate the particular challenges that structural and outcome disparities pose for the Catholic health care ministry. Their existence challenges our core identity and fundamental values. Given our unparalleled understanding of individual and community need and buttressed by our practical ability to bring health and wholeness to individual persons and communities, the Catholic health ministry in the United States has earned its credible moral platform that will be required for leading the transformation of disparity. While necessary, the Affordable Care Act alone is an insufficient behavioral mechanism in transforming disparity. A wholesale effort, one that requires cognitive and emotional investment, is required to address this complicated problem. Using our creative moral imaginations we engage and transform this indicator for the betterment of our entire human ecosystem.

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[2] http://www.rwjf.org/en/about-rwjf/newsroom/features-and-

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articles/Commission/resources/city-maps.html accessed October 5, 2014.

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[4] http://www.cdc.gov/nchs/data/databriefs/db94.htm#prevalence accessed October 2, 2104.

[5] http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6004a2.htm accessed October 2, 2014.

[6] http://eol.org/info/465 accessed August 27, 2014.

[7] http://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/Meaningful_Use.html accessed October 9, 2014. https://www.healthcare.gov/small-businesses/what-do-large-business-owners-need-to-know/ accessed October 9, 2014.

[8] Bernard Mayer, *The Dynamics of Conflict: A Guide to Engagement and Intervention* (San Francisco: Jossey-Bass, 2012), 38.

[9] http://www.youtube.com/watch?v=C53nQB30vIU accessed August 26, 2014.

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[11] Joseph Betancourt and Angela Maina, "The Institute of Medicine Report 'Unequal Treatment': Implications for Academic Health Centers", *The Mount Sinai Journal of Medicine* (2004) 71, no 5., 314-21.

[12] Patient Protection and Affordable Care Act of 2010. Publ No. 111-148, 111th Congress, 124 Stat. 119, 2010.

[13] Bernard Mayer, *The Dynamics of Conflict: a Guide to Engagement and Intervention* (San Francisco: Jossey Bass, 2012), 3-6.

[14] Ibid.

[15] Institute of Medicine http://www.iom.edu/Reports/2013/US-Health-in-International-Perspective-Shorter-Lives-Poorer-Health/Report-Brief010913.aspx accessed, September 19, 2014.

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[18] John Wennberg, *Tracking Medicine* (New York: Oxford, 2010), 11.

[19] J.R. Betancourt, A.W. Maina, "The Institute of Medicine Report 'Unequal Treatment': Implications for Academic Health Centers," *Mount Sinai Journal of Medicine* (October 2004) 71, no.5: 314-21.

[20] K. G. Allred, "Anger and Retaliation in Conflict: The Role of Attribution" in M. Deutsch and P. Coleman, eds. *The Handbook of Conflict Resolution* (San Francisco: Jossey-Bass, 2000), 236-41.

[21] David Williams, "Miles to Go Before We Sleep: Racial Inequities in Health" *Journal of Health and Social Behavior* (2012) 53, no. 3: 279-295.

[22] Lauren Clark, "A Humanizing Gaze for Transcultural Research Will Tell the Story of Health Disparities," *Journal of Transcultural Nursing* (2014) 25, no. 2: 122-8.

# Disability and the Future of Catholic Health Care: Bringing an "Unusual Suspect" to the Center

*Editor's Note: The following two essays were submitted by Alyson Isaksson Capp and Lisa Martinelli to the Graduate Student Essay Contest sponsored by CHA in conjunction with the 2014 Theology and Ethics Colloquium.*

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In 2011, Fr. Tom Nairn of the Catholic Health Association called attention to Howard Brody's critique of the blind spots in mainstream bioethical literature—areas he believes need more engagement from the bioethics community. Disabilities, along with patient-centered care, community dialogue, and environmental and global issues, made Nairn's list of "[i]ssues beyond the "usual suspects,"—"the usual suspects" being end-of-life care, *The Ethical and Religious Directives for Catholic Health Care Services* (*ERDs)*, research ethics, and organizational ethics.[1] Nairn locates disability as an issue bridging right-to-life and social justice concerns of Catholic health care, moving beyond the stalemate that is often perceived between these two perspectives. Citing the United States Conference of Catholic Bishops (USCCB), Nairn points out that a robust ethic of life "implies the defense of other rights which enable the individual with a disability to achieve the fullest measure of personal development of which he or she is capable."[2] He also recognizes Brody's assertion concerning social justice: that "for a person with disabilities, quality of life depends more on the extent to which society is willing to make accommodations than on the severity of the impairment itself."[3] Nairn suggests that "[i]f in the future Catholic health care ethics incorporates more fully the perspective of persons with disabilities into its purview, it may help build better bridges between pro-life advocates and social justice advocates within the church."[4]

What will "[incorporating] more fully the perspective of persons with disabilities" entail for Catholic health care ethicists? I propose three ways in which this might occur. First, it will mean reflecting on the history of how the Catholic Church in general and Catholic health care in particular have and have not adequately listened to persons with disabilities and responded in concrete ways. The Catholic Church has a history of advocating for persons with disabilities on both human rights and social justice fronts, especially through institutional commitments from the Vatican, the USCCB, and Catholic health care. However, Nairn is right in pointing out that there has historically been a divide in Catholic discussions between issues seen more as disability rights (or right-to-life) and social justice issues for persons with disabilities. This may be part of the reason that so much of

Catholic theological and ethical engagement with disability is either confined within personhood discussions or concerns practical matters of inclusivity in the Church and society. Health care ethicists ought to draw from the resources of the Catholic tradition to promote a consistent ethic of life that bridges this divide and takes a more holistic approach to understanding disability. Specifically, Catholic teaching on the diversity of human flourishing needs to be brought into conversation with personhood and social justice concerns.

Second, listening to people with disabilities and those who advocate for them can offer poignant critique and insight into how we care not just for their community, but for other socially marginalized and vulnerable groups and our human community as a whole. In health care, we are constantly caring for people who are at their most vulnerable due to disease and illness. Often, it is a combination of individual attitudes and institutional structures that need reform in order to better serve the entirety of our human community. Attention to the experiences of persons with disabilities on the part of Catholic health care ethicists will engender a response to the "medical model" of disability, which projects a narrow, normative body image and locates disability within individual persons whose bodies stray from this norm. The medical model lens can affect social structures and attitudes present in our health care institutions and among our care providers, inadvertently devaluing and dismissing persons with disabilities. Listening to voices from the disability community can assist Catholic health care ethicists in evaluating and recreating structures and attitudes aimed at inclusivity of diverse bodies while respecting difference. Too often the difference between an archetypal "normative body" (consider the ideal test subject: young, athletic, healthy) and bodies that deviate from this norm is subconsciously translated into a false binary that values a narrow understanding of the human person over embracing a diverse human community.

Third, Catholic health care ethicists need to respond to disability *theologies*. In particular, Eiesland's "disabled God" and Creamer's "limits model" of God and humanity need to be evaluated and critiqued. Eiesland's disability theology takes seriously the resurrection of a savior with an injured body. She states, "In presenting his impaired hands and feet to his startled friends, the resurrected Jesus is revealed as the disabled God."[5] The image and symbol of the disabled God calls us to question normative ideals of embodiment and power present in our Christian heritage, and recognize the diversity and inclusivity of the body of God. Creamer's "limits model" reveals a God who lovingly took on human limits through the Incarnation. For Creamer, "Rather than thinking of limits solely in a negative sense (what we, or what God, cannot do), this perspective offers alternatives for thinking about boundaries and possibilities."[6] While these models of God resonate with some of the experiences of persons with disabilities in the Christian community (both Eiesland and Creamer identify as Christian and as part of the disability community), they also raise questions about more traditional understandings of God as omnipotent, transcendent, and radically other, as well as questions about the human-divine relationship.

As Brody and Nairn suggest, the future of bioethics necessitates critical engagement and dialogue with the disability community.[7] Catholic health care ethicists have a responsibility to weigh in on important bioethical issues highlighted by disability critique. These include, for instance, navigating discussions of difference versus disability, breaking the pervasiveness of the "medical model" within health care institutions and medical education, and instilling an appreciation of human diversity that has room for all bodies in human community. To help frame this response, this article advances the three discussions mentioned above. First comes a discussion of Christian and specifically Catholic contributions and voids in dialogue with the disability community; second, a call to pay attention to the experiences and voices of persons with disabilities in garnering a more inclusive health care environment that is critical of the medical model; and third, a call to engage deeply and perhaps critically in how we understand "God with us" alongside our patients and our health care providers in light of disability theologies that portray God as disabled and/or limited. As full members of the diverse communities served by Catholic health care, whose ineradicable dignity demands our listening ears, persons with disabilities have much to teach Catholic health care ethicists, and it is time that we hear them and respond.

## Disability in Contemporary Christian and Catholic Contexts

As Nairn points out, Catholic social justice movements and right-to-life activists have had the concerns of disability communities on their radar since at least the 1970s.[8] Catholic institutional statements reaffirm the full and ineradicable dignity of all persons including those with physical and cognitive impairments and disabilities, emphasizing the diversity of the body of Christ and full membership in the Church through baptism. Participation in baptism, the Eucharist, and a vocational call to ministry or other Church service for persons with disabilities are reaffirmed in the face of unwelcoming or inconsistent Church practice. Right-to-life concerns are framed through the lens of social justice:

> Defense of the right to life implies the defense of all other rights which enable the individual with the disability to achieve the fullest measure of personal development of which he or she is capable. These include the right to equal opportunity in education, in employment, in housing, and in health care, as well as the right to free access to public accommodations, facilities and services.[9]

Papal statements, both formal and informal, have also addressed the rights and justice issues faced by persons in the disability community.[10] Addressing a group of persons with disabilities in 1984, Pope John Paul II remarked:

> Unquestionably, the quality of a society or civilization is measured by the respect it has for its weakest members… A technically perfect society, where only fully productive members are accepted must be considered totally unworthy of human beings, perverted as it is by a type of discrimination that is no less reprehensible than racial discrimination.

Here John Paul II uses the term "weak" to describe persons with disabilities only in the context of a technocratic society, where "strong" would shallowly equate to being "productive." He denounces this type of society, calling it dehumanizing, and abhors that citizens would be deemed "weak" or "strong" based on productivity.

Also, consider the commitment, as expressed in the *ERDs*, to

> service… and advocacy for those people whose social condition puts them at the margins of our society and makes them particularly vulnerable to discrimination… In particular, the person with mental or physical disabilities, regardless of the cause or severity, must be treated as a unique person of incomparable worth, with the same right to life and to adequate healthcare as all other persons.[11]

These are just two examples of a sustained commitment to advocating for and with persons with disabilities. The Catholic Church and Catholic health care have a foundation for attentiveness to people with disabilities and a commitment to growing an increasingly more adequate response to the social marginalization they still face.

With this solid foundation, Catholic health care ethicists have a starting point for moving beyond discussions that narrowly focus on personhood and disability. Different Christian theological communities are already on board with affirming the full humanity and personhood of persons with varying degrees of physical and mental disabilities, even if they do not agree on all points theological. For example, while Hans Reinders dismisses Thomistic insistence on the rational soul for inclusion in the human community and opts rather to understand personhood in terms of received friendship with God, Miguel Romero insists that a rational soul, with the capability (even if hidden, or not realized until the eschaton) to grow in knowledge and love of God is always present within all human-born persons—thus, grounding personhood similarly to Aquinas.[12] Reflecting on these two positions, E. Lawrence remarks:

> Reinders's allergy to rational-capacities

> language makes him feel more capable of including people with intellectual disabilities more robustly in an account of what it means to be human, while Romero's inclusion of people with intellectual disabilities in a rational-capacities-based account of what it means to be human allows *him* to feel more successful at articulating an inclusive anthropology… maybe it's just a Protestant/Catholic thing at the end of the day.[13]

While these intellectual engagements with Aquinas are important, I argue that these conversations are no longer the kind being asked for by the disability community. What is remarkable in Lawrence's comparison between Reinder's and Romero's discussions is not their disagreement on how to appropriate Aquinas, but on their shared commitment to advocating for the full humanity of persons with disabilities, especially cognitive impairments. With this shared starting point, what is it that the disability community is asking for from theology, and in particular, Catholic health care ethicists? Echoing the work of Eiesland and Creamer, I suggest that structural analysis of models of disability along with the development of new constructs of disability, informed by persons with disabilities themselves, is what we are presently being called to do. While many Christian theologians are in agreement about the full personhood of persons with disabilities (perhaps despite their different appropriations of Aquinas), there are significantly fewer involved in confronting structural barriers to this reality. Here I want to highlight how both Eiesland and Creamer critique the "medical model" of disability, and then illustrate how engaging in constructive dialogue based on the experiences of persons with disabilities can advance other models that are more affirming of diversity within the C/church[14] as the body of Christ.

## Disabled Bodies, Enabled Voices: Listening to the Disability Community

The disability community is as diverse as any human community that refuses to discriminate based on gender, race, ethnicity, age, or socioeconomic status. It includes people with normative and non-normative bodies alike—persons who identify as disabled as well as persons and institutions who support and advocate for them. Leaders in the Catholic Church and Catholic health care can be included in this community. Indeed, to the extent in which health care providers already serve disabled persons within Catholic health care institutions, to the degree inclusive hiring and employment policies are already in place, and to the level at which health care leadership and providers are already formed by an attentiveness to the shared abilities and limits of all persons and patients, some people working in Catholic health care and some Catholic health care institutions are already disability advocates and part of the disability community. However, this is not always the case. The medical model of disability unjustly measures all bodies against an unrealistic norm and treats all non-normative bodies as needing to be fixed. This medical model is still functioning, even if subconsciously, in many health care institutions. I want to call attention to normative body bias in the attitudes of health care providers toward patients with disabilities, and suggest how this bias can be broken down. By engaging the voices of persons with disabilities, we can explore how this bias comes to manifest itself within the attitudes of practitioners and the structural practices of health care delivery. Listening to members of the disability community, voiced here by Eiesland and Creamer, also offers corrective insight for how practitioners can reframe their understandings of bodies, limitedness, and the human condition to be more inclusive of the greater human community.

Catholic health care ethicists need to investigate structures within society, and particularly structures within their own turf—hospitals, clinics, and other health care institutions—that maintain barriers to inclusivity for persons with disabilities. Building on Eiesland's landmark exposition on disability theology, Creamer invites us to reconsider traditional models of disability and their inadequacies. The medical or "functional-limitation" model of disability, all too familiar in health care circles, "is focused around what one can or cannot physically or functionally do" and "is closest to the common sense idea that a disability is what someone has when his or her body or mind does not work properly."[15] This model is severely scrutinized by the disability community because of its reliance on a normative body model—a "biological machine that functions to a greater or lesser extent"—from which people with disabilities deviate. In this model, persons with disabilities are therefore in need of "normalization" to fit societal expectations. The medical model also ignores how environmental and social factors respond to bodies that have been constructed as "normal" and do not as often respond to bodies outside this norm (stairs are "normal"; ramps are not). It is not difficult to see where this model is still perpetuated in our health care institutions today. While there are individuals and groups of health care providers who decisively operate outside of this model, the structures of health care institutions themselves, built upon technological efficiency, standardized rubrics and metrics, and success as relative to normative functioning, perpetuate the "functional-limitation" model. For many persons, especially those who identify as disabled, meeting a specific functional capacity is not directly related to human flourishing or "the good life," and can often times detract from these human spiritual pursuits. The medical model upholds the subconscious mantra of fixing what is broken to restore a normative body, sometimes at the expense of the full human flourishing of those with disabilities in our communities.

To combat this model, some within the disability community have advanced the social or minority group model, which emphasizes "shared experiences of discrimination and oppression."[16] In contrast to the medical model, this model focuses on disability as a sociopolitical category where "disability is not so much about what one can or cannot do but rather is about how individuals are treated in their daily lives and by society at large."[17] The minority group model critiques the ideology of "ableism," which sets up stereotypes of people with disabilities as either living lives less worthy than "able persons" or as saintly, heroic champions of life amidst adversity. The minority group model unmasks these ableist stereotypes, naming disability as social oppression based on an un-interrogated normative body, and recognizes disability as a human rights issue. Despite the preference for the minority model over the medical model among many disability rights activists, Creamer and others note significant shortcomings. She states:

> By emphasizing the social and political nature of disability, the minority model devalues [the physical and emotional reality of impairment.] The minority model suggests that all people with disabilities should accept and even embrace their own disabilities/impairments—after all the impairment is not the (or a) problem.[18]

Creamer advances a new model of disability and embodiment to critique and complement both the medical model and the minority group model. She calls it the "limits model" because it "begins with the notion of limits as a common, indeed quite unsurprising, aspect of being human."[19] I will return to considerations of the "limits model" in the next section. What is important here is recognizing that criticisms from within the disability community can give life to newer models that can change dominant structures and attitudes in health care. Catholic health care ethicists need to understand the social marginalization faced by persons with disabilities from their own particular perspectives and experiences. As Mary Jo Iozzio argues, "If the person adequately and integrally considered is the proper subject of theological ethics then both experience and study qualify as sufficient grounds of authority in and for the moral life."[20] Here I will highlight just two examples of how attention to the experiences of persons with disabilities can shift our moral vision for more inclusive models of disability and humanity.

Eiesland reflects on the life experiences of Diane Devries, a woman born without some of her limbs, to advance an understanding of "bodies of knowledge" that takes seriously the multitude of nonconventional bodies that constitute ordinary existence.[21] Despite negative interpretations of her body suggested by family members and medical professionals, Devries "evaluated her body positively as compact and streamlined," unique and whole."[22] Devries also challenged normative ideas of beauty, remarking on her resemblance to the *Venus de Milo* and asserting herself as "a woman of rare beauty."[23] Eiesland narrates how Devries' self-understanding defies normative models of humanity by exposing the false boundaries between "natural and unnatural experience," whole and incomplete bodies, independence and solidarity, and inner and outer beauty.[24] Devries' critiques are fertile ground for new models of disability and humanity.

Considering "the ethic we need" to cultivate good moral vision, theological ethicist Larry Rassmussen shares the following story of a man with a visible disability while addressing health care professionals about organ transplantation:

> The young man spoke matter-of-factly about his condition and went on to say that in many ancient civilizations the disabled were put to death. This had happened in the United States as well and, even now, in certain cases the disabled were not allowed to live…. Several people challenged him from the floor. His reply was a question: If two persons could avoid death, and could anticipate significantly prolonged life from an organ transplant, and if the only difference between them was that one was notably disabled and the other not, who would receive the transplant?... [B]efore long [the transplant surgeons] began to realize the consequences of their train of thought: The young man who had quietly put the question to them would not, in their considered judgment, be given the transplant that would allow him to live. Quiet moral shock set in as it came clear to them that they had not considered the disabled to be fully persons.[25]

Rassmussen goes on to relay the following reflections from a conference participant: "In the silences between their sentences the participants sensed that they had passed beyond the discussion of ethical, economic, medical, and legal terms to glimpse new horizons of responsibility. Their sense of humanity had expanded."[26] Rassmussen's call to "expand our humanity" by considering issues within the wheelhouse of health care ethics from perspectives within the disability community is a step in the direction of fostering a new moral imagination from which to advance new models of disability and humanity.

By listening closely to the experiences of persons from the disability community as an authoritative source, Catholic health care ethicists can begin to critique discriminatory social structures (like the "medical model" of disability) and offer new models that more adequately express the diversity of ordinary life. This will include integrating new sources of experience (interviews, ethnography, and focus groups) with sources present in the Catholic tradition (papal and bishop statements, the *ERDs*, and work by Catholic theologians on diversity and embodiment). It will mean supporting health care practitioners who resist the dominant "medical model" of disability, along with not being satisfied until the structures that perpetuate the glorification of an abstract normative body are confronted and nuanced. Approaching disability from this perspective makes apparent the limits of focusing narrowly within the personhood discussion, and calls Catholic health care ethicists to ask how the structures and attitudes present within their institutions can invite inclusivity and celebration of diverse bodies within a community. Catholic health care ethicists will also find resources from within a growing group of disability *theologies* from Protestant theologians.

## Disability Theology: The Disabled God and the Limits Model

Disability theology grew out of the liberation felt by the disability community with the passing of the 1990 Americans with Disabilities Act (ADA) coupled with the challenges traditional theology and church structures still posed to inclusivity. While the ADA advanced principles of equal access to employment, buildings, transportation, and communication devices, many churches still harbored practices that restricted some persons with disabilities from ordination and partaking in the Eucharist.[27] As Eiesland remarked in 1994, "For many disabled persons, the church has been a "city on a hill"—physically inaccessible and socially inhospitable.[28] Since the 1990s, church bodies have worked "to promote the full participation of persons with disabilities in the life of the church": for example, in 1995 the U.S. bishops approved *The Guidelines for the Celebration of the Sacraments with Persons with Disabilities*, which clarified and widened access to the sacraments, including ordination and receiving the Eucharist, for persons with disabilities.[29] Though practices within church communities have become more inclusive for persons with disabilities over the past 20 years, especially regarding physical access, normative theological concepts about the body, sin, nature, and grace still project negative images of disability that maintain barriers from full inclusion in the church. As liaisons for an institution of the Catholic Church that serves people with disabilities and advocates for all marginalized persons, Catholic health care ethicists ought to be especially concerned with the effects of these aspects of our Christian heritage that are damaging to the community of disabled persons.

To debunk exclusionary theology and church practices, Eiesland advances the concept of the disabled God. Eiesland explains that the resurrected Jesus Christ, complete with punctured hands and feet and gaping torso, is revealed as God disabled.[30] Her centering upon Christ's resurrection is key, because it is a foundational mystery of our faith commitment and who we say we are as persons working for ministries of the Catholic Church. Through the resurrection, "the disabled God is also the revealer of a new humanity" and "the revelation of true personhood, underscoring the reality that full personhood is fully compatible with the experience of disability."[31] If we take the image of the disabled God seriously, disability cannot be understood as the consequence of sin as it has incorrectly been historically.[32] As Eiesland states, "Our bodies participate in the *imago Dei*, not in spite of our impairments and contingencies, but through them."[33] Additionally, physical avoidance by able-bodied persons of those who are disabled results in a failure to recognize Christ's physical impairment as an intersection point of the equality of all limited bodies. Foreshadowing Creamer's advancement of a limits model of embodiment, Eiesland points out that the limits of our bodies are divinely affirmed, and therefore hope for our eternal and temporal salvation does not rest upon what body we have, as non-conventional as it may be.[34] A final implication of the disabled God is that it affirms the interconnectedness of all of b/Being and the emphasis on right relationships to foster justice.[35] Eiesland argues, "[A] liberation theology of disability is a theology of coalition and struggle in which we identify our unique experiences while also struggling for recognition, inclusion, and acceptance from one another and from the able-bodied society and church."[36]

The social implications of the image of a disabled God are numerous: it evokes an image of "God with and for us" that fully understands the limitedness and diversity of human embodiment and calls for justice for all who are currently marginalized for traits that actually reflect the divine image. The theological implications of the divine God are more complex, and necessitate critical reflection. For example, the notion of a disabled God may seem contradictory to other characteristics we normally use to describe God, like omnipotent, omniscient, radically-other, and literally *unlimited*. For Eiesland, these traditional descriptors are not untrue. She notes, "For people with disabilities who have grasped divine healing as the only liberatory image the traditional church has offered, relinquishing belief in an all-powerful God who could heal, if [God] would, is painful."[37] However, she challenges traditional understandings of omnipotence and power, arguing "the theological implications of the disabled God resist the notion of power as absolute control over human-divine affairs."[38] For Eiesland, the disabled God is a theological representation of who God is in relationship to us that is authentic of Immanuel—"God with us."

Bringing Creamer's description of limitedness to the discussion, we do not have to understand a disabled or limited God in a negative sense. Creamer notes, "When we imagine an unlimited God, there is a subtle implication that the more limits we have, the less we are like God."[39] Therefore, the idea of a limited God is more reflective of the similarity we share in the *imago Dei*. She points out that in many understandings of God, "God took limits willingly… by creating or allowing free will, or by taking on personhood (and death) through Jesus."[40] Creamer posits that "limits do not tell us all that God is," but that recognizing the limits present within the divine allows us to see perseverance, strength, creativity, and a preference for diversity that is more nuanced and like us than "God as radically other" models.[41] In a dialectical fashion, contemplating a limited God offers insight into what it means to be embodied, either as able-bodied, disabled, or somewhere in between, in relationship with the divine and with each other, in a way that was not before possible.

For those who are skeptical that the image of a disabled God can be complementary with traditional, historical, and especially normative or doctrinal understandings of Christology, I offer one more argument for the place of this image of God within our body of ways of knowing. Eiesland shares an epiphany she had of God, a God that to her "bore little resemblance to the God [she] was expecting or the God of [her] dreams."[42] She envisioned "God in a sip-puff wheelchair… the chair used mostly by quadriplegics enabling them to maneuver by blowing and sucking on a strawlike device."[43] Eiesland's theological imagination calls to mind the Jesuit notion of "finding God in all things"—the spiritual understanding that God desires to make God known to us through creation.[44] Finding God in a sip-puff wheelchair is finding a God who embraces diversity and limitedness, identifies with those who face physical and cognitive impairment, and is present with those who are socially marginalized. Finding God in all things also opens us up to multiple and varying ideas of God and our relationship with God that are not mutually exclusive, but converge toward greater understanding.

For Eiesland, it is not problematic to hold the image of the disabled God in tandem with other images—instead, it is liberatory. She sees the incorporation of different models of God as the body of God coming alive, and as an invitation to follow these images to a deeper understanding of ourselves in relationship to God. Through the disabled God, we recognize the common yet diversified limitedness of all of humanity and our complicity in creating and maintaining social structures that refuse to acknowledge this diversity. Additionally, by not interrogating how far the medical model of disability reaches, we overlook the particularity and diversity of those who identify as part of the disability community and fail to recognize these persons as full participants in human community.

Eiesland and Creamer's disability theologies bring up important theological questions that ought to be considered from a Catholic perspective within the context of health care. For example, what does it mean that our resurrected savior is disabled? How does this image of God contextualize more traditional God characteristics like omnipotence? What does it mean to add "disabled God" to our ways of knowing God, not just for people with disabilities, but for all Christians deepening their sense of the divine? Is there room in a Catholic Trinitarian perspective for both a transcendent God and a disabled resurrected Christ? What is the potential role of the Holy Spirit in a Catholic disability theology? The Catholic theological and intellectual tradition is rich with discourses that can address some of these questions. Catholic health care ethicists ought to mine these resources in order to respond to the pervasiveness of the medical model of disability and to disability theologies. While this section is not attempting to advance a Catholic theology of disability at this point, it does carve out the parameters within which such a theology would need to begin and identify potential partners for the conversation.

## Conclusion: Implications for Catholic Health Care

Catholic health care ethicists must take seriously the commitment to persons with disabilities expressed in the *ERDs*.[45] While the foundation for recognizing and promoting the full participation of the diversity of embodied humanity is present within the Catholic tradition, and many persons and institutions that are part of the Church are considered to be on the side of the disability community, Catholic health care ethicists can do more to critique the medical and minority group models of disability, especially when the structures they reside in continue to marginalize our patients, health care providers, and associates with disabilities. Moreover, Catholic health care ethicists have a responsibility to take seriously the theological contributions of disability theology, including the image of the disabled God and the limits model. While these theologies may require critique and reform in light of Catholic theological commitments, we must acknowledge their consistency with other Christian theologies and the resonance they may have with our non-Catholic patients and associates. Further, the re-centering work these theologies have done to break down the false binary relationship perceived between abled and disabled bodies, to consider disability and limits as inherently human and divinely experienced, and above all to bring the voices and experiences of the disability community to the center require a response from the largest group of religiously based health care institutions in the country. The future of Catholic health care ethics calls for structural critique of disability models informed by voices from the disability community, as well as a response to disability theologies. The trajectory for such endeavors ought to be toward embracing a fuller and more diverse human community through advancing a creative and renewed moral imagination of humanity.

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[1] Thomas Nairn, OFM, "Issues Beyond the "Usual Suspects," *Health Progress* 92, no.9, 72.

[2] Ibid., 72. Quoting USCCB, *Pastoral Statement of the US Catholic Bishops on Persons with Disabilities* (Washington DC: USCCB Publications, 2001).

[3] Ibid., 72-73. Citing Howard Brody, *The Future of Bioethics* (New York: Oxford University Press, 2009), 162.

[4] Ibid., 72.

[5] Nancy Eiesland, *The Disabled God: Toward a Liberatory Theology of Disability*, (Nashville, TN: Abingdon Press, 1994),100.

[6] Deborah Beth Creamer, *Disability and Christian Theology: Embodied Limits and Constructive Possibilities*, (New York: Oxford University Press, 2009), 113.

[7] This is especially necessary when considering issues such as pre-implantation and prenatal genetic testing, organ transplantation, enhancement versus therapy, structural justice in health care delivery, inclusive social responsibility and public policy, and social attitudes concerning a/the "normative body."

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[8] The United States Conference of Catholic Bishops has published a *Pastoral Statement of the U.S. Catholic Bishops on Persons with Disabilities, Guidelines for the Celebration of the Sacraments with Persons with Disabilities,* and *Welcome and Justice for Persons with Disabilities: A Framework of Access and Inclusion* in 1978, 1995, and 1998 respectively.

[9] U.S.C.C.B., *Welcome and Justice for Persons with Disabilities*, paragraph 4.

[10] Vatican documents specifically addressing disability include *Conclusions of a Vatican Conference on the Family and Integration of the Disabled* (1999) and *The Person with Disabilities: The Duties of the Civil and Ecclesial Community* (2000). These are in addition to numerous others that mention disability in another context, as well as speeches and shorter statements.

[11] United States Conference of Catholic Bishops, *Ethical and Religious Directives for Catholic Health Care Services,* 5th ed.,11-12.

[12] Hans Reinders, *Receiving the Gift of Friendship: Profound Disability, Theological Anthropology, and Ethics*," (Grand Rapids, MI: Eerdman's, 2008); Miguel Romero, "Aquinas on the *corpus infirmitas*: Broken Flesh," in *Disability in the Christian Tradition*, ed. Brian Brock and John Swinton (Grand Rapids, MI: Eerdman's, 2012), 101-151.

[13] E. Lawrence, "How Are We All Human? Intellectual Disability and Appeals to Aquinas,"*Women in Theology Blog*, March 27, 2013, http://womenintheology.org/2013/03/27/how-are-we-all-human-intellectual-disability-and-appeals-to-aquinas/.

[14] My use of the construct C/church is to reflect both Catholic and Protestant understandings of the body of Christ.

[15] Deborah Beth Creamer, *Disability and Christian Theology: Embodied Limits and Constructive Possibilities*, (New York: Oxford University Press, 2009), 22.

[16] Ibid., 25.

[17] Ibid.

[18] Ibid., 27.

[19] Ibid., 31.

[20] Mary Jo Iozzio, "The Authority of Experience and Study: Persons with Disabilities Adequately and Integrally Considered*,"* in *Louvain Studies* 35, no.1-2 (2011):162.

[21] Eiesland, "The Disabled God," 32-33.

[22] Ibid., 34.

[23] Ibid., 39.

[24] Ibid., 32.

[25] Larry Rassmussen, *Earth-honoring Faith*: *Religious Ethics in a New Key* (Oxford: Oxford University Press, 2013), 143-144. From an unpublished paper by Roy Branson, "Apocalyptic and the Moral Imagination," proceedings from a conference on "Bioethics: Old Models and New," held at Loma Linda University, November 1986, 1-2.

[26] Ibid. This participant is Roy Bronson.

[27] Eiesland, *The Disabled God*, 20.

[28] Ibid.

[29] United States Catholic Conference, *The Guidelines for Celebration of the Sacraments with Persons with Disabilities*, Washington, DC: 1995, p. 19-21, 30-33.

[30] Eiesland, *The Disabled God*, 100.

[31] Ibid.

[32] Ibid., 101.

[33] Ibid.

[34] Ibid., 103.

[35] Ibid.

[36] Ibid., 26.

[37] Ibid., 105.

[38] Ibid., 104.

[39] Creamer, *Disability and Christian Theology*, 112.

[40] Ibid.

[41] Ibid., 112-113.

[42] Ibid., 89.

[43] Ibid.

[44] I am grateful to Dr. Sandra Sullivan-Dunbar and my classmates for this insight

during our seminar course on dependency and agency.

[45.] U.S.C.C.B., *ERDs*, 11-12.

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FEATURE ARTICLE

# Born Blind: The Ethics of Accepting Disabilities in an Age of Genetic Intervention

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## I. Introduction

*His disciples asked him, "Rabbi, who sinned, this man or his parents, that he was born blind?" Jesus answered, "Neither he nor his parents sinned; it is so that the works of God might be made visible through him."*[1] Hermeneutical interpretations of John's Gospel reveal that the man's disability ought not to be considered a punishment, or a sentence to be served, but rather as a theophany, a manifestation of God's power. However, few but the most theologically learned scholars are likely to accept without question that those suffering with debilitating disease or disability are expected to merely accept their condition as reflecting God's grace, without considering the possibility of a cruel, potentially avoidable genetic punishment.[2]

Genetics, as well as enhanced medical and reproductive technologies, have empowered humans not only with the ability to detect diseases in infants which may result in disabilities before symptoms are present, but to do so even before the embryo implants within a mother's womb. While these methods can serve laudable purposes by improving the overall life of a child, genetic screening and selective reproductive processes can also create unnecessary worry, stigma and other kinds of potentially irreparable harm.[3] While not delving into all those harms, this paper will argue that society's obligation to improve the human condition through alleviating human suffering and disease does not presuppose the total elimination of human disability through genetic intervention. This stands in contrast to a seeming fixation with and self-appointed obligation to perfect the human species fostered by advances in technology and genetic research.

## II. Striving to Improve the Human Condition

Understanding what it means to be human and to possess those characteristics and traits which are uniquely and typically human has been an endeavor of philosophers, anthropologists, politicians and theologians practically since the beginning of time. Humanity's ongoing search to define itself is further complicated by its own desire to improve itself—a self not even fully understood—through biomedicine and genetics. In its quest to improve the human condition, humanity wrestles with the attraction of eliminating all unacceptable characteristics and traits not deemed typically human. To say that someone is disabled or that they carry some genetic defect presupposes that there exist criteria for what it means to be *non-disabled*—to be a "normal" human. Accepting persons with disabilities, and even rejecting them, requires societal introspection and at least some recognition of what it means to be human.[4]

## A. The Meaning of Being Human and the Human Condition.

Possessing ideal human characteristics is largely an ambiguous, social construct. From an evolutionary perspective, humans and their embodied nature are distinguished from other animals and are studied according to how they live in relation to their environment, as well as in terms of particular characteristics of human biology.[5] According to Allen Buchanan, humans possess good and bad, common and natural characteristics and dispositions that are impervious to change and external influences, such as the ability to make moral decisions and engage one another socially. As such, without these and other impervious and constant characteristics, a being would not be human.[6]

In addition to reason and reflective capacities, the Judeo-Christian tradition, which has greatly influenced Western thought, holds that what makes human animals *human* is the fact that they are made in the image and likeness of God. This implies that human beings are in special relationship with God and serve as co-creators and stewards for humanity. As stewards, humans have divinely bestowed dominion and are responsible for overseeing things produced for the good of humanity as well for the persons producing them.[7] This dominion presupposes the duty to change and improve life for the rest of humanity.

Hence, both secular and theological perspectives of what it means to be human underscore the need for humans to change and to improve. Both agree that a fundamental human characteristic is the aspiration to become transformed into healthier, more enlightened beings, though there is a lack of normative rules dictating when and which parts of human beings can be changed or even destroyed in its pursuit of self-improvement.[8] What is clear is that human life is challenged and even limited by a host of complex variables, what Walter Doefler refers to as the *human condition*.[9]

The human condition is generally seen, in varying degrees, as broken and flawed. Accordingly, human beings, from the beginning, have been striving to eliminate limitations, alleviate suffering and improve the quality of human life toward greater human fulfillment. An examination of the concepts of human flourishing and the good life will help shed light on the extent to which human beings will go in order to reduce or eliminate limitations—particularly those perceived limitations associated with human disability.[10]

## B. Human Flourishing and the Good Life.

What constitutes a good life and the quest for selecting qualities of human nature which ought to be preserved are questions as old as humanity itself. This paper will not explore the many dimensions of these questions, but will accept for the sake of brevity that those qualities attributed to a good life depend upon what a good life is considered to be. One approach to this question is that a good life is one that promotes and allows for human flourishing.[11]

As with a good life, there is no single view or generally accepted idea of what it means to flourish. Glover aptly states that much of human flourishing relies upon the innate differences attributed to each human and their unique circumstances and environments. With respect to human disability, Glover contends that while all human disabilities involve some functional limitations, the mere presence of a functional limitation does not create a disability, but rather the real disabling quality is found in the impairments or obstacles to human flourishing. Moreover, much of the ability to flourish depends upon the person's reactions and responses to the circumstances and settings that confront them.[12] A flourishing life is not devoid of flaws or limitations, but is rather one that respects those limits and learns to live alongside rather than beneath them.[13]

Throughout most of history, the idea of disability was a medical one. However, the ability for persons with some physical or cognitive limitations to flourish is often impeded by deficient societal settings and negative perceptions of the idea of disability more than by mere biology. The absence of wheelchair ramps, poorly designed transportation systems, and the lack of education and understanding of how to interact with persons having limited functionality impairs human flourishing oftentimes more than the limitation itself. The ability to flourish is further hampered by cultural assumptions of what is *normal,* and society's frequent intolerance, discriminatory practices and preconceived opinions about persons with disabilities and their limitations.[14] Often persons with disabilities, particularly cognitive impairments, function at a level that is often above that of typical or *normal* persons and yet, they are still considered to have a disability.

This presumes that living with a disability or with a person who has a disability is somehow a denial of life's goodness. Persons with disabilities can flourish on their own, because what constitutes flourishing is dependent largely on preferences.[15] A disability which renders someone unable to engage in a particular activity may not be a disability at all if the person would not value that activity or want to engage in it even if they could.[16] Most persons with disabilities along with their families and loved ones express a sincere appreciation for the lives they live. The joy that someone with a disability experiences in the ordinary course of their lives—the joy they appreciate—is markedly different from that which the able-bodied experience. Hence, they are misunderstood or ignored altogether. The negative views and social responses to those with disabilities are based upon prejudice and ignorance.[17] People rarely talk about the positive, relational life experiences of persons with disabilities, but rather, persons with disabilities are often referred to in relation to their perceived deficiencies. In addition to the importance of human flourishing, the good life ought to be defined in terms of the health of human relationships.

The relationships between persons with disabilities and their families, the persons they choose as friends, and the communities within which they live can enhance and enrich the ability to flourish beyond any biological characteristic or quality. Martina Holder-Franz warns that society must guard against creating a myth of normality that values people excessively for their biological characteristics and qualities. She contends, instead, that life is vulnerable and relational, and persons with disabilities ought not to be judged by their *ability,* but rather by their *availability* for relationships. Personhood is sustained by relationship, and what sustains relationship is love.[18]

Christian theology teaches that humans are to live in communion with each other, to share with one another and to serve one another. The Great Commandment is about humans and their loving relationship to their neighbor.[19] Human flourishing demands loving relationships that promote dignity, friendship and caring. Rather than adhering to attitudinal barriers which create roadblocks to flourishing, humans must be motivated by a belief in the goodness of creation and the image of a God that is present in everyone in order to reveal God's face and to allow His grace to emerge.[20] The grace that appears allows humanity to witness the truth that each person is limited and broken in some manner and is need of others. This enables persons with disabilities (and all persons) to live what Matt Edmonds calls a *graceful life.*[21] This togetherness promotes interdependence that welcomes the presence of God, and helps to eliminate the fear that often pervades the willingness to get to know a person with a disability. Christian interdependence honors the value of all individuals—despite their limitations—not by what they can or can't do, but by simply being who they are.[22] Interdependence means persons are dependent upon God and each other, but it also acknowledges God's *dependence* upon everyone to be agents for God's healing throughout the world.[23] The idea of healing and curing are seminal objectives often employed when supporters seek to justify improvements to the human condition, particularly when those genetic improvements seek to eliminate disease and suffering associated with perceived disabilities.

## III. Perspectives on Improving the Human Condition

Although there are inherent cultural and societal difficulties in determining which human characteristics render a person able-bodied or disabled, or *normal* versus *abnormal*, applying a medical model that relies on the human genetic code will at least presuppose a prescribed, predictable baseline of acceptable and healthy genetic characteristics. Influenced by the bioethical principles of beneficence, autonomy, justice and non-maleficence, genetic technology and medicine undergird the duty to improve the human condition by preventing mortality, morbidity, and disability.[24] The concepts of healing and cure seem to undergird these efforts to improve, and often run parallel to or intersect with the history of eugenics.

### A. To Heal Or To Cure.

The distinction between curing and healing is rarely clear, and, in fact, it is frequently blurred. When the word *cure* appears in the English language, it typically refers to the eradication of a disease and its symptoms such that a person is restored to the same health and physical condition as before the disease appeared, or as if it hadn't appeared at all.[25] If a cure seeks to eliminate disease and suffering, it must be distinguished from *healing* which, as Nancy Lane asserts, is a *process* of integration and wholeness and not simply being free from illness, and does not necessarily manifest physically. According to Lane, healing is freedom from false and unrealistic expectations.[26] Healing brings about grace, peace and well-being, and often involves finding a sense of meaning and purpose—a spiritual wholeness, but not necessarily a cure.[27] A healing may or may not include a cure, and, clearly, a cure may or may not include a healing.

Understanding the nebulous demarcation line between these two words is critical to the discussion of genetic interventions and their effect on human disabilities. Because society traditionally perceives healing very narrowly and typically recognizes it only in the physical improvements and manifestations of those persons with an easily detectable disorder or disability, its inclination is to focus on only the physical effects of the healing or cure. This tendency severely limits how society ought to see the collateral impact to the able-bodied as well as disabled persons who are spiritually healed, even in the absence of a cure.[28]

To find a cure, society turns to the medical arts. Exercising prudence, religious traditions advocate and approve of the view that humans can intervene as stewards of life and co-creators to cure *and* heal, seeing medical professionals as God's agents on earth.[29] However, as St. Basil the Great warned, there are limits to the effectiveness of the medical arts and persons cannot turn the pursuit of health and cure, or even longer life, into an all-consuming idol. Medicine as a healing art gives glory to God, but if fails to help, all hope for relief cannot be placed in this art. Humans must look to God's will.[30] This is a critical warning, because while the New Testament is filled with accounts of Jesus' curative miracles as divine revelation, not everyone who was sick was cured, and yet many were inwardly healed.[31]

It is in society's best interest to place a high value on health and well-being, to value good health over ill-health, and to reduce morbidity and improve overall health. However, as Wilkinson contends, placing a high value on good health ought not to imply that those who are ill or disabled are valued less. Similarly, while most people would prefer being able-bodied to being disabled, and healthy rather than unhealthy, the fact of the matter is that much of what is considered *normal* and *able* are subject to normative beliefs,[32] and even the most robust members of society are only temporarily able. In time, all are broken to some degree.[33] So a principle issue for those who seek to improve the human condition is whether it is in the purview of society to decide the state of any future person by eliminating disability through genetic intervention. The notion of choosing who and what constitutes an appropriate human life has many very deep roots in eugenics.[34]

## B. The Impact of Eugenics.

The term *eugenics* was coined in the late 19th century by Sir Francis Galton to refer to those who were "well born" and was applied to the study of heredity to improve the genetic makeup of the human race by removing undesirable individuals from the societal gene pool. Later, the U.S. Supreme Court decision in 1927 upholding the eradication of all "imbeciles" bolstered and fortified this movement.[35] During this period in history, it became an obligation and reproductive duty of all good citizens who were the "right type" to leave behind their blood in the world through procreation and to prevent the "wrong type" of person from procreating. Forced sterilization laws mandated that prisoners, residents of mental facilities and paupers—those deemed manifestly unfit—be irreversibly prohibited from reproducing.[36]

It wasn't until Adolf Hitler's perverse and notorious world of eugenics, genocide, and mass murder resulted in the systematic execution of those persons classified as "defective" that the American eugenics movement began to die. Any association with Nazi eugenics was shunned. Genetic advances today are resurrecting eugenic-like conduct and reintroducing it into American culture—largely through prenatal testing, and the killing of embryos and abortion of fetuses with genetic disorders. However, termination of these unfit lives is performed without any honest acknowledgement of the eugenic nature of the activity.[37]

Today eugenics is typically characterized as a study of the conditions under which the human condition or the biological character of the human race and its offspring can be improved. Often influenced by political and social controls, *positive eugenics* occurs when the goal of a eugenic activity is to produce humans of high quality by increasing the "good" gene pool in order to enhance the human condition. *Negative eugenics* seeks to reduce undesirable genes that cause disease and disability in order to prevent harm to the human race by minimizing the number of sick babies born.[38] The positive and negative aspects of eugenics and the purpose of each type determine whether disability is seen as a defect requiring enhancement or elimination, a disability that seeks healing, or as an illness seeking a cure.

The connection between genetics and historical eugenic philosophies, which associated social ills with the prevalence of mental and physical defects, undergirds much of contemporary thinking concerning treatment of persons with disabilities.[39] Ethicists who argue against eliminating disability through both positive or negative eugenics properly contend that genetically screening out and deselecting disability, or even attempting to correct characteristics of disability in the absence of a diagnosis, expresses discriminatory views that the person is unfit. And even those ethicists who support negative eugenics admit that continued efforts to reduce the number of sick babies will merely increase the list of characteristics, qualities, and conditions to be eliminated, adding to the discriminatory effect.

Since the primary goal of eugenics is the identification, manipulation and perhaps elimination of certain prescribed human characteristics, those who possess certain disabilities are once again viewed as having lives that are less meaningful, have less purpose, and are deemed unworthy to live.[40] Consequently, eugenicists would support deselecting embryos believed to carry a disabling condition because it would avoid creating a low-quality life. This is a preposterous belief, and as Wilkinson asserts, the happiest person with a disability will likely experience a better quality of life than the most miserable able-bodied person.[41] Similarly, Paul Ramsey considered all forms of genetic control unethical arguing that positive eugenics suffered from cultural influences determining normalcy and defect, and instead favored very limited negative eugenics through voluntary childlessness and reducing the number of pregnancies if a known genetic predisposition existed. Some ethicists see eugenics as genetics in the absence of Christian thought.[42] Although many do, clearly not all methods employed to improve the human condition through genetic interventions carry the indicia of questionable eugenics.

## IV. Methods of Improving the Human Condition

There are many ways to improve the human condition and create opportunities for humans to flourish that do not entail biological interventions. Nevertheless, disease avoidance typically involves some physical interventions. Some of these will now be briefly considered.

### A. Newborn Screening and Prenatal Testing.

Today, state-sponsored newborn screening tests are administered to more than 4 million infants per year.[43] By acting on the screening results, presymptomatic identification and diagnosis can help to establish early treatments—including dietary modifications—to avert a serious disability, moderate the effects of a disease and improve prognosis, and assist parents in their future reproductive planning.[44]

Policymakers favor screening only for serious disorders with effects that can be mitigated or even reversed before clinical onset. There is an overwhelming acceptance of mandatory newborn screening initiatives for those conditions where morbidity is reduced, disabilities are avoided and beneficial treatments and protocols exist.[45] As such, newborn screening provides a mechanism for human flourishing which serves to avoid needless suffering for newborn children and their families in order to improve the human condition without controversy.

Carrier and prenatal testing can determine the risk of having a child with a rare congenital condition if both parents carry the same gene—oftentimes ahead of pregnancy, but always before the child is born. Information from carrier testing can assist parents in making informed, proactive, reproductive and even lifestyle choices which may reduce the prevalence of a disease. In addition, testing may afford parents the opportunity to prepare financially as well as psychologically for the arrival of a child with special needs if they decide to have their own biological child.[46]

Carrier and prenatal testing shift the parental decision away from deciding which early intervention or treatment is most appropriate to having a healthy baby as in the case of newborn screening, to deciding whether to have *any* baby at all. It is this *selective* quality that carries both ethical and theological implications.

## B. Selective Reproduction.

While most genetic intervention is seen as a positive method of promoting flourishing for both existing and future children, selective reproduction makes it possible for parents to literally choose to have one desirable child instead of another child with perceived undesirable characteristics and disabilities, thereby allowing one person to come into being while another may die.[47] Reducing the conflict that selective reproduction techniques create between flourishing and negative eugenics requires some examination of what parents really owe to their children.[48]

Most parents want what is best for their child and accept the obligation to provide for them according to their ability. However, it is not clear whether the duty to provide what is best includes genetic interventions to eliminate a disability, or to choose not to have a child with a known disability all together. Since a good life entails the ability to flourish, then it logically follows that parents have a duty to provide opportunities for their children to flourish, and any intercession beyond that, such as genetic interventions to correct or eliminate conditions that do not clearly threaten human flourishing, may go too far and represent nothing more than parental hubris.[49]

Certain prenatal testing procedures call into question the parental duty to facilitate flourishing. Procedures such as amniocentesis can result in the prenatal diagnosis of Down-syndrome and other congenital defects that cannot be treated and reversed in utero. As a result, termination of the pregnancy is often viewed as the only “therapy” for these conditions. In addition, pre-implantation genetic diagnosis (PGD), which occurs prior to the embryo entering the womb, forces parents to decide which embryo to implant and which one to destroy.[50] Wilkinson aptly contends that selective reproduction such as PGD and prenatal testing accompanied by selective termination present the opportunity for present and future children to be discarded and replaced with a more desirable variety.[51] Thus, the ability to choose future children through selective reproduction is vastly different from providing opportunities for human flourishing by improving the condition of children who currently exist through newborn screening, preventive medicine, and treatment.

Inherited genetic modification (IGM) or somatic gene therapy makes it possible to modify the state of a baby's genetic blueprint from what the baby *would* have become to what it will become.[52] While it has been developed as a treatment because it can affect inheritable gene material, it also possesses all of the critical components of an enhancement that seeks to improve the human condition rather than only treat a human being.[53]

## V. Ethical and Theological Dimensions of Deselecting Disability.

Deselecting children and denying them life in an attempt to improve the human condition and minimize suffering by reducing the number of persons with disabilities threatens, among other things, the notion of uniqueness. It further conveys the message that the world would be "improved" and better off if persons with disabilities were never born.[54] The presumption that a person with a disability experiences human suffering, that all suffering is bad, and that suffering eclipses human flourishing ought to cause humanity to reconsider its view of what it means to suffer.

Human flourishing does not entail genetic perfection through the absence of disability. Rather, it entails embracing all life as a gift through acceptance and tolerance. Just as it would be unconscionable to abandon a child who becomes disabled, rejecting a possible future child with a disability is equally so.[55] Pervasive negative images of persons with disabilities and the abhorrent notion that they impose burdens on the human condition that should be eliminated through genetic interventions must be examined through ethical and theological lenses.

### A. The Gift of Life and Human Suffering.

To say that a human life is only as good as the person's ability to flourish implies that much of the good turns on the choices available to that person. Hans Reinders considers human goodness and asserts, instead, that what accounts for having a good life is not whether a person would choose to live their life again, if given the choice, but rather the recognition that life is good because it simply *is* good. The goodness of life is a gift of divine goodness—a *donum*—a gift and giftedness that has a divine purpose.[56] Life as a gift is received from God who intended it to be good and is grounded in God's act of giving.[57]

Nevertheless, God's gifting of the good life does not vitiate humanity's free will and choice. As with any gift, humans have the choice to accept the gift. The goodness of life turns on humanity's willingness to learn how to receive His gift, respond to Him, and find peace with Him. God's gift of life does not come with a voucher; it cannot be returned if it isn't exactly what was desired or doesn't fit quite right.

Gracious recipients of gifts know that the highest compliment a person can pay the giver is to thoroughly enjoy and love the gift. So it is that the highest recognition a human can give God is to thoroughly love their good life.[58]

Writing in a more secular vein, William May refers to parenthood as the 'openness to the unbidden' in that the ethic of giftedness includes the notion that parents ought to appreciate children as gifts and accept them as they are given. The gift of life is not as an object of design to pick and choose as a person might pick and choose the color scheme of a newly built home or office. Parental love cannot be contingent on the desirability of the attributes and talents of the child. Flourishing requires love—two types of parental love according to May—accepting love and transforming love. Accepting love affirms the goodness within the gift of life and transforming love seeks the well-being of the child.[59]

Transforming love speaks to the obligation to heal and strive for curative measures as necessary and to advance medical treatments for the sake of the health of the child, but not as an attempt at boundless mastery or domination over the giftedness of the child. The obligation to heal or help cure a sick child now does not equate to rejection of the future gifts of life of later born children, nor does it grant a parent authority to change the genetic makeup of this gift.

But humanity struggles with the idea of expressing authentic appreciation for an arguably good gift of life that brings with it physical and/or emotional pain and suffering.[60] Even though the presumption that persons with disabilities experience suffering that is desperate for relief is shaped by society's understanding of normalcy and individuals' perception of personal flourishing, reducing suffering and preventing impairment are still primary goals of humanity. As is often the case with those who have a disability or are different in some apparent way, the greatest suffering one can experience is the pain of isolation and rejection, or the pain from the knowledge that one belongs to a class that is not welcomed or valued. Yet, the truth is, only those with disabilities know whether or not they suffer.[61] Theological concepts of suffering can help to shape patterns of interaction and understanding between those with disabilities and those without.[62]

Biblical support of virtuous suffering—the idea that impairment and disability are signs of divine election, as reflected in the passage from St. John's Gospel at the beginning of this paper—may help to sanction acceptance among persons with disabilities, but does little to foster acceptance between the community and even the parents of those with disabilities.[63] What needs to happen is a universal acceptance and recognition that those with disabilities, especially those who are perceived to suffer greatly, are divine gifts and, as St. Augustine claimed, humans are not defined by their mental and physical perfection or the degree to which those capacities are painfully deformed and disabled, but rather are grounded in their decent from Adam. As

such, they should not be shunned, but rather seen as God's special works.
By fixating only on the perceived deficiencies and limitations of those with disabilities, society's adherence to artificial normative constructs of what constitutes avoidable pain and suffering fails to recognize a significant value and grace-filled opportunity that those with disabilities bring to living. As the foot-washing scene in the New Testament emphasizes, the essence of Christian life is one of community and service to one another. This service does not define one person as superior or inferior to the other, but rather establishes a mode of service involving the sharing of gifts between friends—bundling the notions of love of neighbor and Christian friendship.[64] The theological concept of suffering creates an opportunity for Christian service and friendship, not for genetic intervention and eugenic eradication.

Nothing is more unimaginable than the broken and disabled Christ as described by Isaiah. Unable to move or speak, he was profoundly and grotesquely disabled, and like many who suffer stigmatization from their afflictions, he was avoided, spurned and accustomed to infirmity. Like the fear that many have for those with disability, people hid their faces from him.[65] And despite being dispossessed of his power and abandoned by nearly everyone, he was restored to greatness through his suffering. For those who struggle to understand the role that pain and suffering play in Christian life, it is often understood best when someone lives through their most painful and challenging experiences. It is then that they find God, somewhere in the pain. The pain is used for some transformed good. Richard Rohr teaches that pain is counterintuitive. People must go down before they can know the joy that is above.[66] It is in this transformation that pain and suffering take on a deeper meaning. It is through the integration of the giftedness of life, living in service of others, and the grace that comes from human suffering that Christianity emerges to embrace human disability as a divine blessing, not as a loathsome disease.

## B. Christian Acceptance of Disabilities.

Conservative and liberal Christian theologians differ considerably as to whether or not the duty to improve the human condition and promote human flourishing includes genetic interventions that interfere with human disability and, if so, what amount and type is appropriate. The spectrum ranges from the view that humans are co-creators and that the call of the faithful is to work for the most desirable future for humankind measured by God's destiny, to the thought that genetic technology and the ability to provide for a better future is justified through brotherly love and beneficence, and to the view that technological advances do not permit humans to *play God,*[67] but rather to *play human* as God intended. This means humans have a stewardship duty to restore, change, and sustain the world.[68] In addition, it is critical to understand that for most Christian perspectives, particularly Roman Catholic, attempting to improve the human condition by deselecting an embryo likely to have a genetic defect is the functional equivalent of killing a disabled person.[69]

As discussed earlier, life is a not a matter of chance, it is a gift, and human procreation is not a game where the winner takes all and parents who give birth to a child with a congenital disorder or who learn of a genetic defect are forced to become gracious losers.[70] Rather, since all human life is a gift from God and parents who receive God's gift cannot lament the fact that the child lacks certain characteristics, or ideal traits, or that the child has a serious disability.[71]

Since humans are in fact God's co-creators through the gift of procreation, then perhaps the goal of humans is to move away from wanting supremacy over nature and to move instead towards the ultimate good and human flourishing considering the eschatological dimension that Aquinas suggested. However, the Catholic Church does approve genetic interventions that do not contradict Catholic reproductive norms provided that their principle aim is curative, palliative or preventive, and possibly even geared towards elimination of a genetic disorder from a family line, without harming human integrity or worsening a person's life condition.[72]

The Magisterium of the Catholic Church professes to hold science and research in positive esteem and urges that harmony between science and indispensable human values be established. It sees science as an expression of man's dominion over creation, according to the *Catechism of the Catholic Church.*[73] However, the Church warns that from the moment of conception, every living embryo must be respected as if it were human in an absolute way because humans are the only creature that God wished for himself and no one has the right to destroy that life.[74] In addition, the *Catechism of the Catholic Church* further teaches that it is morally unacceptable to put an end to the lives of the disabled or handicapped, regardless of the means or motives.[75] Hence, genetic interventions that seek to eradicate human disability through de-selection or other means are prohibited. All human life that is affected by disability or handicap is to be treated with special respect.[76]

As already mentioned, the Catholic Church and other Christian faiths recognize the duty to be stewards of creation and to improve the human condition through activities that demonstrate a continual respect for human life. By applying the gifts of wisdom and prudence, humans can come to understand the future that God intended for creation, the scope of human flourishing, and the appropriateness of human actions toward that end.[77] Deanne-Drummond correctly suggests that moral justification for improving the human condition through genetic technology can find guidance within the theological framework of virtue ethics. Prudence (recognized as experiential reasoning), justice (balancing equality with good), fortitude (the strength to do what is right), and temperance (self-restraint in the face of impulse) are gifts of the Holy Spirit that are infused by God. Applying these theologically informed virtues is necessary to moral decision-making vis-à-vis genetics and the implications for those with disabilities.[78] Prudence and wisdom will open the eyes blinded by eugenic notions of perfection to see that the human condition is *unconditional* and acceptance of God's gift is not conditioned on achieving human perfection.[79]

The concept of eschatology underscores the notion that humans cannot, and should not attempt, to make themselves perfect on their own. Death will always eclipse confidence in genetic technology and interventions.[80] The Babel Principle, according to Nigel Cameron and Amy DeBaets, warns the human race against such arrogant attempts to circumvent God and achieve perfection on its own.[81]

The Christian community must remain committed to the gifts of the Holy Spirit and to acting in ways that are welcoming and accepting of all persons with disabilities along with their families.[82] When society welcomes these, they welcome God. According to Deanne-Drummond, Stanley Hauerwas and other disability theologians echo that the presence of God is in everyone – especially the disabled, and when they are accepted, welcomed and sustained, God is similarly affected. God's being is the being of the disabled.[83]

## VI. Conclusion

Human beings have long pondered the existence of pain and suffering in the world, and considered the presence of disability to be someone's punishment or curse.[84] The desire to eradicate suffering and transform the human condition has motivated society, science, and medicine throughout the centuries and appears to have found its culmination in genetic technology. Humanity's interest, however, in improving the human condition and alleviating suffering appears to have stretched beyond what is morally acceptable insofar as genetic interventions and modifications seek to eliminate human suffering by presupposing the elimination of those with disability.

Accepting and embracing human disabilities requires a shift away from a culture that pursues perfection at all costs and requires recognition that the beauty found in the person with a disability is not dependent upon human perfection, but rather, divine grace.[85] Human perfection ought not to be a human aspiration, but rather an exclusive entitlement belonging to the one true holder of Divine sovereignty. Prudence allows those who seek perfection by eliminating the imperfect to see that there is much to learn from those with disabilities and the tendency to render them worthless or unfit is wrong.

The Creator of the human condition is indeed a God of and for the broken and disabled in all of humankind. And in fact, Jesus reminded his disciples that God's ultimate power and presence was reflected in the man born blind. His blindness, like the myriad of disabilities present in contemporary society, did not emanate from his sin or the sin of his parents, and was not something to be de-selected and destroyed. Rather, his healing and the lessons learned from that healing were signs of God's preeminence. Human limitations and sinfulness resulting from the Fall can disable human senses and prevent persons from seeing and hearing God's tender voice, not a vengeful voice, that whispers to his people in a sound of fine silence.[86] These same limitations can be overcome whenever people set aside their prejudices and see with the eyes of the disabled, and listen with their ears to God' divine message.

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[1] *John 9:2-3.*

[2] (Rohr, *Things Hidden: Scripture as Spirituality*, 9-12-25).

[3] (Baily and Murray, *Ethics and Newborn Genetic Screening*, 160-169, 206, 260-266).

[4] (Black, *The Healing Homiletic,* 43-47).

[5] (Kraebnick, *The Idea of Nature. Debates About Biotechnology and the Environment*, 49-56).

[6] (Buchanan, *Beyond Humanity*, 143-152).

[7] *Genesis 1:26-29.*

[8] (Buchanan, 115-139).

[9] (Swinton and Brock, *Theology, Disability and the New Genetics. Why Science Needs the Church*, 117-130).

[10] (Buchanan, 130-139).

[11] (Glover, *Choosing Children. Genes, Disability and Design*, 87-99).

[12] (Glover, 4-18).

[13] (Cole-Turner, *Transhumanism and Transcendence, 52*-59).

[14] (Swinton and Brock, 44-54).

[15] (Eiesland, *The Disabled God,* 49-67).

[16] (Wilkinson, *Choosing Tomorrow's Children*, 63-75).

[17] (Swinton and Brock, 163, 165, 205); (Eiesland, *Human Disability,* 206-208).

[18] (Swinton and Brock, 57-64).

[19] *Matthew 22:34-40.*

[20] (Au, *By Way of the Heart*, 41-48).

[21] (Matt Edmonds, *A Theological Diagnosis. A New Direction on Genetic Therapy, 'Disability' and the Ethics of Healing*, 29-42, 130).

[22] (Eiesland, 19, 36-40, 52-63).

[23] (Black, 32-42).

[24] (Deanne-Drummond, 1-5, 140-148).

[25] (Edmonds, 153- 168).

[26] (Edmonds, 42-43, 160-161).

[27] (Black, 50-56).

[28] (Eiesland, 105-122).

[29] (Glover, 171-179).

[30] (Cole-Turner, *Design and Destiny*, 2, 11, 83-88).

[31] (Martos, *Doors to the Sacred. A Historical Introduction to the Sacraments in the Catholic Church*, 328-343).

[32] (Wilkinson, *Choosing Tomorrow's Children*, 159-166); (Baily and Murray, 299-302).

[33] (Eisland, *Human Disability and the Service of God*, 123-140).

[34] (Deanne-Drummond, *Genetics and Christian Ethics,* 55-75).

[35] *Buck v. Bell*, 274 U.S. 200 (1927).

[36] (Sandel, *The Case Against Perfection in Ethics in the Age of Genetic Engineering*, 63-68); (Edmonds, *A Theological Diagnosis*, 50-51).

[37] (Swinton and Brock, 96-106).

[38] (Wilkinson, 149-163); (Deanne-Drummond, *Genetics and Christian Ethics,* 60-74).

[39] (Brownlee, *Disability and Disadvantage,* 319-320).

[40] (Wilkinson, 149-185).

[41] (Wilkinson, 58-70).

[42] (Wilkinson, 170-173); (Deanne-Drummond, *Genetics and Christian Ethics,* 55-67).

[43] (Baily and Murray, 1-30, 100, 212-214).

[44] (Baily and Murray, 93-116); (Deanne-Drummond, *Genetics and Christian Ethics,* 77-88)

[45] (Baily and Murray, 129-130,223-224, 264); (Deanne-Drummond, 81-84).

[46] (Baily and Murray, 292-303).

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[47] (Wilkinson, 5-7, 177); (Deanne-Drummond, 5-8).

[48] (Glover, 14-18, 39-51).

[49] (Glover, 14-18, 39-74).

[50] (Deanne-Drummond, Genetics and Christian Ethics, 86-88, 108-110, 116).

[51] (Wilkinson, 129-141).

[53] (Deanne-Drummond, Genetics and Christian Ethics, 125-138); (Wilkinson, 186-196); (Green, Babies by Design, 33-42).

[54] (Wilkinson, 166-179).

[55] (Wilkinson, 29-40).

[56] (Swinton and Brock, 30, 163-178); (Cole-Turner, *Design and Destiny,* 85-88).

[57] *Genesis 1:1-31.*

[58] (Rolheiser, *Against an Infinite Horizon. The Finger of God in Our Everyday Lives,* 78-81).

[59] (Sandel, 45-62).

[60] (Black, 19-26).

[61] (Black, 19-32).

[62] (Eiesland, *Human Disability and the Service of God,* 105-122).

[63] (Eiesland, *The Disabled God,* 69-86).

[64] (Au, 153-167).

[65] *Isaiah 53: 2-5.*

[66] (Rohr, 12-25).

[67] (Green, *Babies by Design, The Ethics of Genetic Choice*, 171-196).

[68] (Deanne-Drummond*, Genetics and Christian Ethics*, 30-45).

[69] (Wilkinson, 13-15,173-179); (Deanne-Drummond, *Genetics and Christian Ethics*, 86-88).

[70] (Wilkinson, 134-146).

[71] (Wilkinson, 37-47).

[72] (Glover, 172-191); (Cole-Turner, *Design and Destiny,* 12-15, 60-65).

[73] *Catechism of the Catholic Church,* n.2293, n. 2294, p.552; (Cole-Turner, *Design and Destiny*, 83-84).

[74] (Cole-Turner, *Design and Destiny,* 52-65, 98).

[75] *Catechism of the Catholic Church*, n.2277, p.549.

[76] *Catechism of the Catholic Church,* n.2276, p.549.

[77] (Deanne-Drummond, *Genetics and Christian Ethics*, 44-54, 149-150).

[78] (Deanne-Drummond*, Genetics and Christian Ethics*, 1-26).

[79] (Wilkinson, 21-35).

[80] (Cole-Turner, *Design and Destiny,* 99-105).

[81] (Cole-Turner, *Design and Destiny*, 1-6, 106-107).

[82] (Deanne-Drummond, *Genetics and Christian Ethics*, 41-54).

[83] (Deanne-Drummond*, Genetics and Christian Ethics*, 112-124).

[84] (Eiesland, *The Disabled God,* 67-71, 83-84, 92).

[85] (Deanne-Drummond*, Genetics and Christian Ethics*, 85-86, 101-115).

[86] *1Kings 19:11-13.*

# Summary Report on a Theological-Ethical Discussion of the CDF "Principles for Collaboration with Non-Catholic Entities in the Provision of Health Care Services"

On August 29, 2014, CHA gathered a small group of theologians and ethicists to discuss the CDF "Principles for Collaboration with Non-Catholic Entities in the Provision of Health Care Services," released on February 17, 2014. Participating in the discussion were Peter Cataldo, Fr. Gerald Coleman, Johnny Cox, John Gallagher, Fr. Tom Kopfensteiner, James LeGrys, Therese Lysaught, Fr. Michael Place and CHA staff Sr. Patricia Talone, Lisa Gilden, Ron Hamel and Fr. Thomas Nairn. Sr. Mary Haddad was an observer in her role as Senior Director for Sponsor Services and Ellen Schlanker was an observer in her role as Director of Communications.

The goals for the meeting were four: 1) achieve greater understanding of the Principles; 2) identify and attempt to clarify areas of ambiguity; 3) identify possible implications of individual principles for Catholic health care; and, 4) achieve some consensus on the authority of the document. The basis for the discussion was a commentary on the Principles by Peter Cataldo, with regard to which there was considerable consensus. Dr. Cataldo's commentary informs many of the comments below.

1. **General Observations.**

   - There are ecclesiological issues behind the Principles that very much need to be surfaced and addressed, especially the relation of the Church to the world. A "Christ and Culture" typology might be a fruitful way to clarify and better understand various conceptions of the relationship of the Church to the world. Partnerships are not just health care issues; they also involve the nature of the Church. For example, they can be vehicles of the Church's engagement with the world.

   - The Principles are an application of the Principle of Cooperation to a particular set of circumstances—collaborations with other-than-Catholic health care organizations.

   - There is nothing particularly new in the Principles. They generally reflect and affirm what has been and is being done across Catholic health care with regard to collaborations with non-Catholic entities.

- The Prologue to the Principles recognizes the need in the current health care environment for Catholic health care organizations to collaborate with non-Catholic health care institutions, "even establishing joint working arrangements in which the Catholic and non-Catholic entities are full partners." Such collaborations are not inherently wrong.

- The Prologue also recognizes that collaborations with non-Catholic entities may be pursued primarily to meet the health care needs of the community. The survival of the Catholic entity need not be at stake.

- The Principles are "intended to ensure that Catholic healthcare institutions neither cooperate immorally with the unacceptable procedures conducted in other healthcare entities with which they may be connected nor cause scandal as a result of their collaboration with such other entities."

- The Prologue also explicitly recognizes the complexity and variety of arrangements and the need to apply the Principles, the Principle of Cooperation, and the *Ethical and Religious Directives* on a case-by-case basis.

- The Principles in themselves are not likely to have any adverse implications for Catholic health care.

- The Principles do not have the weight/authority that other documents issued from the CDF might have. The Principles do not constitute a *Responsum* to the *Dubium* that was sent to the CDF by the then president of the USCCB on April 15, 2013. They are not written on CDF stationary, are not signed or dated by the Prefect of the Congregation, nor is there any indication that they were seen and approved by the Pope—all usual with a typical *Responsum*. Rather, the Principles are an advisory document to the bishops intended, as the letter from Cardinal Mueller states, "to assist the Bishops of the United States in considering their teaching and governing responsibilities in the development and reorganization of Catholic health care organizations or systems." At least one church authority has commented that the Principles do not rise to the same status as the *Ethical and Religious Directives* themselves.

2. **The Principles Themselves.**

What follows reflects the understanding of the Principles by those participating in the meeting. Of course, this understanding is subject to further elucidation by the bishops and or by the CDF.

The ordering of the Principles below reflects the order of the group's discussion and also reflects a certain logic in the clustering of related principles.

- #7 speaks to a preference for collaborations with other Catholic entities or with those non-Catholic entities that function in a manner consistent with Church teaching.

- #2 underscores the illicit nature of *formal cooperation* and the liciety of *material cooperation* under certain circumstances.

- #5 has been interpreted narrowly by some as specifying the only legitimate reason for cooperation, that is, the survival of the Catholic entity. This interpretation, however, does not make sense in light of the tradition. Rather, what the principle seems to be saying is that if the financial viability and survival of the Catholic organization is at issue, then the reason for cooperation with a non-Catholic organization should be survivability and not "financial advantage or financial stability for its own sake apart from the real risk of financial collapse" (Cataldo). Survival need not be limited to immediate survival. It could include future survival if certain actions are not taken today.

- #6 begins by stating that a Catholic health care organization cannot engage in the wrongdoing of another organization either by intending the moral object of the act or by providing essential circumstances for the wrongdoing to occur in and through the collaboration, even if not intending the wrongdoing (Cataldo).

  This principle also states that an arrangement where the Catholic entity is a subsidiary of a non-Catholic parent is not ruled out a priori nor is Catholic participation on the board, so long as the parent functions in a manner consistent with Catholic ethical principles (Cataldo).

- #10 describes theological scandal.

- #11 indicates representatives of a Catholic institution on a board of a mixed system should **recuse** themselves from any decisions "proximately connected with immoral procedures." Of course, they may also vote against such decisions, but this is not morally required.

This principle also "recognizes the moral legitimacy of a Catholic health institution involved in the direction of a health care system with subsidiaries that do not adhere to the ethical principles of the Catholic Church. Being part of the governance of such a system in itself does not constitute illicit cooperation in any immoral activity performed by the non-Catholic subsidiaries" (Cataldo).

- #17 states that diocesan bishops must be informed of prospective agreements and cessation of agreements. In addition, local ordinaries ought to be in communication with one another over these matters as appropriate.

- Several principles identify the **presence** of ***formal cooperation***. Formal cooperation is likely present if:

    - #1, an administrator or board, in an arrangement that includes both Catholic and non-Catholic components, **makes decisions that correspond to actions that are themselves immoral and enter into the formality of the immoral actions**, even if those decisions apply only to the non-Catholic facilities within the organization.

      This principle also recognizes the moral agency of institutions (by analogy) and the individuals in leadership and governance who act on behalf of the institutions. Hence, it is appropriate to assess the cooperation in evil on the part of both administrators and the institution itself.

    - #3, the directors of a Catholic health care system give **approval** to the wrongdoing of the non-Catholic party even if their remote/ultimate intention is different from the wrongdoing, and most likely is itself a good intention. This seems to be describing implicit formal cooperation.

    - #4, the administrator or board of an organization comprised of both Catholic and non-Catholic facilities officially **consent** to immoral procedures within the system or facility under his/her/their authority.

      This does not preclude the possibility of licit material cooperation on the part of non-administrative employees (or board members or administrators for that matter).

- #8, a Catholic health care system takes into itself an institution that has not agreed to abide by the ethical principles articulated by the Church. If the formerly non-Catholic institution engages in wrongdoing under the auspices of the Catholic institution of which it is now a part, then the Catholic organization engages in formal cooperation.

- #9, the administrators or employees of a Catholic entity are directly involved in wrongdoing at a secular entity of the same system, though this could also be immediate material cooperation. When becoming part of such an organization, the Catholic entity must ensure prior to finalizing the arrangement that it will not be involved directly in immoral procedures, that its facilities and other resources not be used for such procedures, and that none of its members will be required to make referrals (to be distinguished from providing information that is in the public domain). Attention must be given to the possibility of scandal.

- #12, board members **set up or help set up an administrative body**, such as a board of directors, independent or supposedly independent of the system or institution, that will **oversee the provision** of immoral services. This is to be distinguished from the Catholic party's making clear to its potential non-Catholic partner that it cannot be involved in the governance, management, financing or profit, or provision of any other essential circumstances regarding immoral procedures. These must be isolated from the Catholic entity. As Cataldo explains: "Informing a prospective partner what it cannot do if the collaboration is to take place is an act of separation and removal by the Catholic institution from the immoral procedures, not formal cooperation in them.

  Informing the prospective non-Catholic partner what it cannot do if it is to avoid illicit cooperation is in itself a good act."

  - #13, board members **set up or help set up an entity**, such as a clinic, independent or supposedly independent of the system or institution, that will be **engaged in immoral procedures**.

- Several principles describe **what ought to be done if Catholic health care institutions or board members are faced with or are involved in formal cooperation.** If such is the case, the institution or board members must

  - #14: **extricate** itself/themselves as soon as possible from the situation.

  - #15: **Extrication is compatible with remaining in the system/arrangement** so long as the Catholic party is not formally cooperating. The formal cooperation has ceased.

  - #16: When extricating itself from formal cooperation by reconstituting the system as non-Catholic, the Catholic organization must do what it can to ensure that the secular entity **adheres as closely as possible to principles of the natural moral law.** This suggests the moral legitimacy of a statement of common values.

    This principle also recognizes that a corporation can have moral responsibility and engage in moral acts through individual board members.

3. **Other Observations on the Principles Themselves.**

- It would have been helpful had there been a theological and ecclesiological context within which to interpret the Principles.

- It would have been helpful had a distinction been made between ownership and control. The mere fact of ownership is not decisive. Control is much more so.

- What does "governing" mean? There is civil governance and ecclesiological governance. There is need for greater clarity in this regard. What is the bishop's role in governance? This is not clear.

- There is some confusion in the language of “board members” and “administrators,” “directors” and the responsibilities of boards. Also, are the boards that are referred to system boards or facility boards? There is some lack of clarity regarding levels of governance in the document.

- There is a critical difference between collaborating with organizations that may be engaged in some wrongdoing and cooperating in the wrongdoing.

- The CDF’s Principles demonstrate that “purist” views of the Principle of Cooperation are a distortion of the tradition.

- Is there a sufficient distinction between “toleration” and “approval”? The document might have benefitted from some discussion of toleration.

4. **Discussion of Other Issues Related to the Principles.**

   - New structures are needed to help Catholic health care work more collaboratively and constructively with the bishops and to enhance trust between both. Catholic health care needs to work on credibility and transparency with local bishops.

   - The Principle of Cooperation may not be sufficient by itself to deal with the ethical issues arising in the new health care environment in which Catholic health care finds itself. We may also need to draw upon other theological resources from within the tradition.

# Inclusion and Use of Race and Ethnicity in Ethics Consultation Research

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## Introduction

Racial/ethnic disparities in health, health care, and outcomes of care have been extensively documented in the United States. Research clearly demonstrates that racial/ethnic minority groups in the United States disproportionately bear the burden of poor health, limited access and poor quality of care and have worse health outcomes than whites even after accounting for socioeconomic and other demographic factors (AHRQ, 2013; IOM 2009). For example, African-American patients are less likely than white patients to receive recommended care including A1c and lipid testing and are more likely to suffer long-term complications of diabetes such as diabetic retinopathy (Harris, 1998), lower extremity amputations (Gornick, 1996;Young, 2003) and chronic kidney disease (AHRQ, 2013;Virning, 2002). These racial disparities in diabetes care have been attributed to patient socioeconomic characteristics and comorbidity, with a large portion of residual disparities attributed to within rather than between physician difference effects (Sequist, 2008).

Given this body of research documenting the health disparities present in health care and the fact that 76 percent of ethics consultations are performed by medical professionals (physicians [34 percent], nurses [31 percent], social workers [11 percent]) involved in direct patient care (Fox et al., 2007), it is reasonable to question whether the same underlying factors that contribute to health disparities also influence ethics consultations. The purpose of this paper is to 1) report on a systematic literature review examining whether race/ethnicity is used or documented in empirical research on ethics consultations, and 2) explore possible implications of these findings related to clinical ethics consultation.

As of 2007, about 95 percent of hospitals had, or were in the process of developing, an ethics consultation service (Fox et al., 2007). Ethics consultation is defined by The American Society of Bioethics and Humanities (ASBH, 1998) as "a service to help patients, families, surrogates, professionals or other involved persons address uncertainty or conflict regarding value-laden issues that emerge in a health care setting" (p.3). The focus of clinical ethics consultation is to "address the ethical issues involved in a specific clinical case … to improve the process and outcomes of patients' care by helping to identify, analyze, and resolve ethical problems" (Fletcher & Siegler, 1996, p.4). Some of the common ethical problems include end-of-life issues (futility, withdrawal of life-sustaining treatment), respect for patient autonomy, and conflict resolution. Religious and cultural issues, professional (mis)conduct, and confidentiality issues have also been shown as important (though less common) triggers of ethics consultations (DuVal et al., 2001). In ethics consultations, the consultant will gather relevant data and attempt to clarify concepts and related normative issues. It is also the role of the consultant to build consensus among those involved by ensuring that everyone's values and opinions are voiced in a clear and equitable manner. The consultant will then identify and present a range of morally acceptable options (ASBH, 1998).

In most health care systems anyone providing direct patient care (e.g. doctors, residents, nurses, social workers) and patients or their families can request ethics consultation, yet most requests (68 percent) are made by physicians (Swetz et al, 2007; Repenshek, 2009). Some prior research suggests that physicians can influence or be a barrier to other staff requesting general consultations (Gacki-Smith & Gordon, et al., 2005; Danis et al., 2008). Research also shows that clinicians hold strong convictions for or against the use of ethics consultations, unrelated to an individual case, which may affect the utilization of the ethics consultation service (Orlowski et al., 2006; Davies & Hudson, 1999). It is, however, not clear whether decisions related to the use of ethics consultations, or the outcome of the ethics consultation itself, are affected by race.

## Literature Review Methods

We conducted a systematic review of published peer reviewed empirical research on ethics consultation that included or examined racial/ethnic information using Ovid, Medline and PubMed database. With the help of experienced librarians, a search was done using the following key words: *'ethics consultation,' 'ethics case consultation,' 'clinical ethic,' 'ethics service,' race, racial, and ethnicity*. Terms for racial and ethnic groups were searched individually and also by exploding the terms "race" and "ethnicity" to include any alternate names associated with these terms. The search was then narrowed to include only original empirical human studies published in English between 1990-2012.

## Results

Our search resulted in nine original articles (Aulisio et al., 2000; Carrese & Perkins, 2003; Casarett & Siegler, 1999; DuVal et al., 2001; Perkins, 2008; Romano et al., 2009; Schneiderman et al., 2000; Schneiderman et al., 2003; Thompson et al., 2004 ). Despite filtering for "original empirical human studies" in our systematic literature review, other types of articles were returned in our search. Table 1 summarizes the nine articles found and highlights how race was used in each one. Of the nine, only four were original empirical research (DuVal et al., 2001; Romano et al., 2009; Schneiderman et al., 2003; Schneiderman et al., 2000). The majority of the studies collected race but did not use race as a study variable anywhere in the analysis. The paper most pertinent to the topic of patient race in ethics consultation was a theoretical paper looking at ethics consultation and cultural diversity (Carrese, 2003), three articles focused on potential cultural factors that influence patient decision making (Rosell, 2005; Nolan et al., 2005; Davis, 1996) and one article looked at cultural issues in a clinician's ethical education (Yarbrough, 2007). Our review of published empirical studies on ethics consultation found no articles that specifically address whether race/ethnicity is used or documented in relationship to ethics consultations nor the question of whether the same underlying factors that contribute to racial/ethnic health disparities influence ethics consultations.

## Discussion

### *Possible Reasons for Lack of Empirical Research*

With race and ethnicity being increasingly implicated in disparities in health care delivery and given that ethics consultation is predominantly provided by these same providers, why is race/ethnicity seemingly ignored in the empirical arena of ethics consultations and bioethics?

Although the underlying reasons for neglecting race/ethnicity in ethics consultation are not clear, opinions range from the view that the race/ethnicity of patients is not an important ethical issue for the field, to issues related to confidentiality and data de-identification. Johnstone & Kanitsaki (2010) explored the neglect of racism in health care ethics. The authors proposed the idea of an "illusion of non-racism in health care" and the tendency of health care providers to overestimate their ability to be unbiased and ethical when responding to unethical situations. Yet, the empirical evidence shows that clinicians may have biases that influence decision making and the care they provide (Green et al., 2007;Khan et al., 2008). As noted earlier, because most clinical ethics consultations are provided by health care providers (e.g. physicians, nurses, social workers) who may hold similar biases as other health care providers, ignoring race/ethnicity in the field could eliminate the ability to standardize care and implement quality improvement assessments in ethics consultation (Appiah and Gutmann, 1996). Given the prevalence of well-documented health care disparities among racial/ethnic minorities, their vulnerability to biased or differential treatment suggests these are the very groups who would likely benefit from ethics services and resources.

Racial and ethnic disparities in health care that go beyond socioeconomic status (SES) and access to quality care are well documented as well (Mays et al., 2006). Patient race has been shown to influence physician treatment recommendations (Schulman et al., 1999) and the patient-physician relationship (Cooper-Patrick et al., 1999). The Institute of Medicine (IOM) recommends the collection of race, ethnicity, and language in order to track and address these racial and ethnic disparities in health care (IOM, 2009). Unfortunately, we cannot determine if racial/ethnic disparities actually exist in ethics consultations because these data are not being collected or documented.

Many studies have looked at the prevalence of ethics consultations, patient gender, patient diagnosis, reason for and effects of the consultation (Repenshek, 2011;Tapper, et al., 2010; Fox et al., 2007; Swetz et al., 2007; Schneiderman, 2006). Yet only one study (Orr et al., 1996) documented race in its demographic information.  It is interesting to note that there is more research on the race/ethnicity of physicians and their attitudes towards ethics consultations than there is on race/ethnicity of patients and their attitudes toward the same (Braun et al., 2010; DuVal et al., 2004).

### *Implications for Practice*

The problem stretches beyond the inability to measure racial disparities in relationship to ethics consultations.  We are missing valuable data in our evaluation of the ethics consultation as it relates to patient outcomes, patient and provider satisfaction, and emerging issues central to the needs of the patient and their family.  If ethics is a significant aspect of "the reflective process by which a particular cultural group's moral proclivities and choices are systematically interpreted, examined, and defended" (Carter & Klugman, 2001), then it is clear that ethics does not transcend culture; the two are inextricably linked.

As the United States becomes increasingly diverse, the likelihood that physicians and patients are from different cultural groups is also higher. Research has shown that patients in race-concordance relationships with their doctor have higher overall satisfaction with care, report more comprehensive care and feel more engaged in decision-making (Cooper-Patrick, 1999; Saha, 1999).  The importance of understanding cultural differences transcends variances in communication styles and language. A patient's racial/ethnic and cultural background may influence his/her perceptions of illness, meaning of life and death, how they interpret the roles of clinicians or family, and how they make decisions related to their physical and psychological care.  While one cannot stereotype a group and make assumptions about individuals in that group, it is important to understand the cultural differences persons might bring to the ethical issue and use that understanding appropriate to the consultation process itself (Singer & Blackhall, 2001).

There is a wealth of literature on cultural aspects of bioethics, including, for example, documentation of the historical roots of African American mistrust of the health care system to strategies for discussing negative information with Navajo patients (Eiser & Ellis, 2007; Carrese & Rhodes, 2000). Although a summary of this literature is beyond the scope of this paper, the consensus seems to be that there are ethical issues that are culturally specific that need to be addressed by bioethics (Jecker, 1995; Carter, 2004; Eiser, 2007).  For example, a qualitative study on advance care planning (Perkins et al., 2001) found that minorities are less educated about, and have less understanding of, advance directives. Specifically, African Americans are less trustful that their wishes will be respected, and Mexican Americans are less likely to have shared their wishes with family members.

While the theoretical attention given to the role of race in ethics consultations seems to bring to light its importance, the empirical research, data collection, and reporting practices of ethics consultation services do not support this sentiment. Empirical research (Saha, 2003; Van Ryn & Burke, 2000; Doescher, 2000) has shown that several factors – including mistrust, perceived discrimination, unfair treatment and poor provider-patient communication – have been associated with racial/ethnic disparities in health and health outcomes. All of these factors have ethical dimensions that may require consultation (DuVal et al., 2001). By not having the empirical research from which to respond, ethics consultation services run the risk of reinforcing systems that are informed only by the dominant set of attitudes, behaviors, social structures, ideologies and the requisite power needed to maintain them (Guider, 2001).

Bioethical analyses, for example, are often crafted in relationship to four traditional principles: respect for autonomy, beneficence, non-maleficence, and justice–principles that are generally accepted as applicable to all patients (Beauchamp & Childress, 2008). However, different cultural groups may hold varying views of the four principles with some groups influenced more by their collective cultural views of certain health behaviors or procedures (Wolf, 1999; Fagan, 2004). Some researchers have found cultural differences in medical communication. Wieringen and colleagues, for example reported less concern/empathy providing consultation to ethnic minority patients. Additionally, variance exists with regard to the balancing and trumping function of these principles based on the culture that circumscribes the interpretation of the principles e.g., traditional Hmong culture's deference to family matriarch in patient decision-making at the expense of personal autonomy (Barrett, 1998).

As Wolf (1999) argues, "It seems that the individual patient-by-patient way in which bioethics has applied principles such as autonomy and beneficence has obscured patterns of stereotyping and prejudice that are themselves ethical problems" (p.70). Some of the racial disparities we see today in patient trust and confidence or help-seeking behaviors have been influenced in part by historical ethical failures in upholding these principles in the clinical decision making process (Jones, 2010). Research, for example, shows that physician biases influence their clinical judgment and care decisions (Schulman et al, 1999; van Ryn, 2002). Bioethics analyses need to consider the centrality of race/ethnicity and gender and how these factors occasion unethical health care and research behaviors. Moreover, such analyses need to be informed by the troubling historical contributions of medicine and biomedical sciences to racial and gender disparities (Wolf 1999). Wolf observes that "there is no such thing as a patient without race, ethnicity, and gender… A bioethics ignoring race, ethnicity, and gender will fail in moral analysis of these cases" (p.70). Mays (2012) observes that African-Americans are not a monolithic group, but a population with diverse ethical values, shaped by different experiences and historical contextual factors that influence important bioethical spheres including their personhood, individual autonomy and moral views (Randell, 2012; Wiredu, 1992a; Wiredu, 1992b). Instead of focusing on understanding their mistrust of the health care system, according to May and colleagues (2012), there is a need for a “science-based bioethics for conducting research on African-American[s]” that goes further than merely examining why African-Americans mistrust the health care system.

*Recommendations*

Research is needed to examine racial/ethnic disparities in ethics consultation services and whether there are breakdowns in provider/patient communication and institutional policy that increase ethical and value conflicts for these groups. A better understanding of facilitation and barriers to ethics consultation faced by racial/ethnic groups is also needed. Finally, a critical self-reflection may be needed to examine whether ethics consultation services themselves are adequately informed about their own “blind-spots” to recognize that the consultation service is embedded in a system that already delivers demonstrably inequitable treatment. Further research is needed to look at racial and ethnic variations in: (1) the central ethical issues presented in ethic consultations, (2) how these issues are communicated, (3) how the need/desire for ethics consultation is communicated, and (4) the relationship between patient satisfaction and racial concordance of the consultant[s]. In doing so, it will then be possible to assess the effectiveness of cultural competency/engagement training for those engaged in ethics consultation as a mere first step.

Changes, such as the development of a universal code for ethics consultation with specific subcategories of types of ethic consultations, are needed in order to successfully document and analyze these consultations and the patients and clinicians involved. Such efforts would be an entry point for important ongoing quality improvement studies, both internally and as an entire discipline. Determining and interpreting the prevalence of ethics consultations in different ethnic/racial groups is, therefore, just the beginning—nonetheless, an important one.

*Conclusion*

In reviewing the literature, we found very limited documentation of race/ethnicity in ethics consultation empirical studies. Indeed, reporting of race/ethnicity in ethics consultation literature is almost non-existent. The paucity of research in this area may highlight limited awareness, referral, and utilization of ethics consultations in our health care system. Collecting data on race and ethnicity would provide a framework to connect cultural issues and strategies in bioethics with actual practices. If disparities do exist, we need to examine why. Based on the increasing racial/ethnic inequalities in health, quality of care, outcomes of care, and the increasing diversity and complexities in clinical care, a better understanding of racial/ethnic and cultural factors in ethics consultation research is needed.

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Table 1. Summary of Key Ethics Consultation and Race/Ethnicity Articles

| *Article* | *Study Type* | *Role of Ethics Consultation* | *Role of Race* | *Race/Ethnicity used as study variable* |
|---|---|---|---|---|
| DuVal et al., 2001 | Empirical | Focused on factors associated with request of ethics consultation | Physician Race collected | Yes (physician race) |
| Romano et al., 2009 | Empirical | Explores effect of mandatory ethics consultation policy | Collected | No |
| Schneiderman et al., 2003 | Empirical | Effects of ethics consultation in ICU | Collected | No |
| Schneiderman et al., 2000 | Empirical | Effects of ethics consultation in ICU | Collected | No |
| Perkins, 2008 | Case Study | Importance of using patient culture in ethics consultation | Highlights importance of culture. | No |
| Casarett & Siegler, 1999 | Case Study | Describes the role of an ethics consultation service in withholding resuscitation | Collected | No |
| Thompson et al., 2004 | Conference Summary | Makes recommendations to call for consultation when needed | Recognizes influences of patient culture. | No |
| Carrese & Perkins, 2003 | Editorial | Looks at ethics consultation and cultural diversity | Focuses on importance of culture in consultation. | No |
| Aulisio et al., 2000 | Position Paper | Proposes standards for bioethics consultation services | Importance of cultural sensitivity in ethics consultation services. | No |

## Care at the End of Life

Care at the end of life has been receiving considerable attention of late, much of it in the popular press, especially the *New York Times*. At the end of August, the *Times* ran an article describing how coverage for end-of-life conversations is gaining ground with some private insurers, for Medicaid patients in some states, and, possibly, for Medicare patients if the Centers for Medicare and Medicaid Services approves a request from the American Medical Association. The A.M.A. creates billing codes for medical services and recently created codes for end-of-life conversations which were submitted to Medicare (Pam Belluck, “Coverage for End-of-Life Talks Gaining Ground,” August 30, 2014). A decision should come this fall. If positive, it will likely give impetus to additional private insurers to follow suit. Studies have shown that end-of-life conversations can make a difference in how people die.

Several articles appeared in September and October, most of a narrative nature—accounts of the dying experience of a relative or acquaintance—but with a lesson to be learned. One such account was titled “When It’s the Doctor Who Can’t Let Go” (Theresa Brown, September 7, 2014). The author concludes the piece this way: “Physicians also need to recognize that there are occasions when the patient’s fate is not, in the end, the doctor’s work. Every patient deserves care on his own terms, for each patient’s life, and death, is his own.” Writing from the opposite perspective, to some degree, a physician whose father was active in the medical futility movement, writes that “physicians need to reclaim some of the turf they have ceded to patients and families.” He goes on to say that his father would have approved of the recommendations in the recent Institute of Medicine Report, “Dying in America,” but he also would have wanted more: “for doctors to be bolder and more courageous, to see their duty not simply as providing options but as making sure patients got the most appropriate care, even if that meant saying no to specific demands” (Barron H. Lerner, “When Medicine Is Futile,” September 19, 2014; see “Letters: Who Speaks for Dying Patients,” September 25, 2014).

Another account (Nina Bernstein, “Fighting to Honor a Father’s Last Wish: To Die at Home,” September 25, 2014) describes in some length how virtually every aspect of the health care system—hospitals, nursing homes, home health agencies, Medicare and Medicaid—conspired against the possibility of the author’s father’s dying at home as he so fervently wished. She observes that most of the medical spending was wasteful and could have been redirected to what would have been beneficial—social services and supports. Public money, she maintains, benefits health care businesses, but not necessarily patients.

This same point was made a week later in a *New York Times* editorial commenting on Ms. Bernstein’s experience. The editors write: “Two issues raised by this case seem particularly troubling. Virtually every institution took actions that served its own needs, not the patient's. And there was no coordination between Medicare and Medicaid." They go on to mention the Institute of Medicine Report that calls "for an overhaul of how care is delivered near the end of life to eliminate the mismatch between what patients and families need and the services they can obtain."

Atul Gawande provides another personal account—"The Best Possible Day" (October 5, 2014), and also discusses what he learned from over 200 interviews he conducted in preparation for his latest book, *Being Mortal: Medicine and What Matters in the End.* He writes: "And among the many things I learned, here are the two most fundamental. First, in medicine and society, we have failed to recognize that people have priorities that they need us to serve besides just living longer. Second, the best way to learn those priorities is to ask about them. Hence the wide expert agreement that payment systems should enable health professionals to take sufficient time to have such discussions and tune care accordingly." What might some of these priorities be? He goes on to explain: "Medicine has forgotten how vital such matters are to people as they approach life's end. People want to share memories, pass on wisdoms and keepsakes, connect with loved ones, and to make some last contributions to the world. The moments are among life's most important, for both the dying and those left behind. And the way we in medicine deny people these moments, out of obtuseness and neglect, should be cause for our unending shame."

Several of these accounts come in the wake of the Institute of Medicine's 500-page report, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life* (September 2014) and even make reference to it. The report states that "broad improvements to end-of-life care are within reach" and it identifies not only specific areas for improvement but also concrete steps that can be taken to reach this goal.

Shortly after the IOM Report was released, Brittany Maynard, diagnosed with terminal brain cancer, announced in a CNN op-ed that she will end her own life on November 1 in order to avoid a long, debilitating, and painful dying. In an op-ed in the *New York Times* on October 11, 2014, columnist Ross Douthat, after referencing Maynard, asks "why, in a society where individualism seems to be carrying the day, is the right that Maynard intends to exercise still confined to just a handful of states? Why has assisted suicide's advance been slow, when on other social issues the landscape has shifted dramatically in a libertarian direction?" ("The Last Right: Why America Is Moving Slowly on Assisted Suicide"). Meanwhile, Compassion and Choices seems to be gearing up in California for another attempt to legalize physician-assisted suicide. While eschewing physician-assisted suicide and euthanasia, physician Ezekiel Emanuel writes in an article ("Why I Hope to Die at 75") in *The Atlantic* that he wants to die at 75 in order to not experience the physical and mental diminishment and debilitation of old age.

At the other end of the spectrum is Judie Brown writing in a column on the Renew America website ("The Big Scare in Obamacare," October 14, 2014) that Catholic health care's Supportive Care Coalition is part of a coalition urging Congress to pass legislation to replace costly life-saving care for the ill with palliative care, all in an effort to save money. She writes: "[L]et's just say that when the Supportive Care Coalition's homepage tells everybody that it is the 'voice of advocacy for palliative care,' we can translate that into meaning that it is part of the effort to redefine pain management that moderates the pain for the ill and dying into terminal medication for cost-saving purposes. It's euthanasia with a pretty face."

The IOM Report and the various accounts noted above underscore the need for significant efforts to improve care at the end of life. While advances have been made over the years, there is clearly still a long way to go. The IOM Report offers something of a blueprint—a blueprint that needs to be embraced and implemented by a host of individuals from politicians to government agencies to health care organizations and health care professionals. Improving care at the end of life in order to reduce if not completely eliminate the types of experiences narrated in the above accounts is the responsibility of all. Without taking up this responsibility, change will not come or will come much more slowly. Bringing about the needed improvements is a challenge in itself. It is only complicated by those who denigrate palliative as "euthanasia with a pretty face" or those who elevate the exercise of autonomy and control above so many other considerations.

R.H.

# Of Note

### Lawmakers Push Increased Access to Emergency Contraception

The Emergency Contraception Access and Education Act of 2014 was introduced in the Senate by five Democratic senators: Patty Murray (D-Wash.), Elizabeth Warren (D-Mass.), Barbara Boxer (D-Calf.), Richard Blumenthal (D-Conn.), and Cory Booker (D-N.J.). The act states that any hospital receiving Medicaid or Medicare funding must provide information and access to emergency contraception for survivors of sexual assault regardless of their ability to pay for the treatment. Senator Murray told *Time*, "Emergency contraception is a critical part of these family planning choices and it's time Republicans join us in supporting this safe and responsible means of preventing unintended pregnancies." It is likely the bill will face opposition from congressional Republicans. Charlotte Alter, *Time*, September 24, 2014

### Too Many People Die in Hospital Instead of Home. Here's Why.

Patients in the New York metropolitan area choose aggressive treatments more often than patients in other parts of the country. This means more doctor visits, more treatments, more expenses, and more people dying in the hospital. Why does this happen more in New York? Specialists at the Dartmouth Healthcare Atlas surfaced two possible reasons: the area has a lot of hospital beds and the medical "culture" consists of highly trained specialists who see it as their job to *cure* illness. At Mount Sinai Hospital, the chair of surgery requires staff to discuss hospice options with all terminally ill patients. Dr. Diane Meier, a geriatric specialist at Mount Sinai, added, "All of medicine needs to be willing to say, 'Why did this person with end-stage dementia have three or four hospitalizations in the last three months of life and die in the intensive care unit? This was a terrible experience for the patient and family. A lot of unnecessary suffering'". Fred Mogul, *Kaiser Health News*, Sept. 22, 2014

### Transplant Providers Dispute Changes to Allocating Donated Livers

In the United States, 6,256 adults received liver transplants in 2012 but 3,002 patients died or were removed from the waitlist. The United Network for Organ Sharing (UNOS), a not-for-profit that contracts with the federal government to oversee the organ transplant system, wrote a preliminary proposal to address the geographic disparity of organ transplants. The proposal seeks to address the disparity by reducing the number of allocation districts from 11 to as few as four. Currently, doctors will advise more affluent patients to temporarily relocate to a state with higher transplant rates. A bipartisan group of more than 50 members of Congress criticized the proposal. They said if the new standards were implemented, "more organs for transplant would travel significantly longer distances, areas with high organ-donation rates would be disproportionately affected, organs would experience longer cold ischemic times, and the proposal may not have the desired effect of lowering overall waitlist mortality." Sabriya Rice, *Modern Healthcare*, Sept. 22, 2014

### Dying In America Is Harder Than It Has To Be, IOM Says

The Institute of Medicine released a report, "Dying in America", that offers a new "life-cycle model of advance care planning." The report suggests that end-of-life conversations begin when people receive their driver's license and make a decision regarding organ donation. As a person reaches other milestones in life, turning 18, getting married or having children, a counselor or social worker should continue the conversation. The report concludes that the American health care system is not equipped to properly care for patients at the end of life. There are not enough doctors proficient in palliative care. There is reluctance among doctors to have honest end-of-life conversations. There is not enough financial or organizational support for dying patients. The committee offers a recommendation to combat these systemic problems. Regardless of specialty, all clinicians "should be competent in basic palliative care, including communication skills, interprofessional collaboration, and symptom management." Jenny Gold, *Kaiser Health News*, Sept. 17, 2014

### The Trials of Stem Cell Therapy, Stem Cells: Plenty of Hope, but Halting Progress

Progress in stem cell therapy research has been slow. Dr. Ellen Feigal, senior vice president of research and development at the California Institute of Regenerative Medicine, says that research has shown stem cell therapy can be safe so "Now what we want to know is: Will it work, and will it be better than what's already out there?" According to Dr. Charles Murry, co-director of the Institute of Stem Cell and Regenerative Medicine at the University of Washington, beyond bone marrow transplant, few therapies have been effective. In 2006, Shinya Yamanaka, a Japanese researcher and Nobel Prize winner, discovered a way to revert adult cells back into stem cells. This allowed new avenues of research including reproducing cells from patients with specific problems and studying the disease in a petri dish. The most cost-effective way to deliver therapy is still unknown. A recent study at the University of Miami found that patients using donor stem cells did just as well as patients injected with their own stem cells. This finding, if supported further, could mean that stems cells created in large batches could be used for multiple patients, lowering the cost of treatment. Dr. David Scadden, co-director of the Harvard Stem Cell Institute, warns that "progress comes in fits and starts," just like the "war on cancer" declared in 1971. Karen Weintraub, *The New York Times*, September 15, 2014

## NIH Issues Finalized Policy On Genomic Data Sharing

The National Institutes of Health issued a final NIH Genomic Data Sharing (GDS) policy to promote data sharing. The policy is expected to assist researchers in turning data into knowledge, products and procedures to improve the health of patients across the country. A key to the new GDS policy is that researchers obtain informed consent of participants to share information for possible future studies. Along with verifying informed consent, the policy ensures that data was collected legally and in an ethically appropriate manner with personal identifiers removed. Kathy Hudson, NIH deputy director for science, outreach and policy, said "Everyone is eager to see the incredible deluge of molecular discoveries about disease translated into prevention, diagnostics, and therapeutics for patients. The collective knowledge achieved through data sharing benefits researchers and patients alike, but it must be done carefully. Aug. 27, 2014, [www.nih.gov/news/health/aug2014/od-27.htm](www.nih.gov/news/health/aug2014/od-27.htm)

## Obamacare Has Reduced the Uninsured Rate for Virtually Everyone – Except Kids

According to the Urban Institute Health Reform Monitoring Survey, the rate of uninsured adults dropped 4 percent over the past year but the rate of uninsured children has barely changed. Fortunately the rate of uninsured children was low before the ACA implementation, about 7 percent, due to programs like the Children's Health Insurance Program (CHIP). Among enrollees in the new health insurance exchanges, only 6 percent are children. The Urban Institute and the Georgetown University Center for Children and Families see that increased Medicaid enrollment could cover more children who could not afford the high insurance premiums offered under CHIP. The researchers estimate that 55 percent of uninsured children are eligible for public coverage through Medicaid or CHIP. As the ACA continues to take effect, lawmakers have to decide how to fund CHIP after the 2015 fiscal year. Advocates of CHIP are concerned that lawmakers will cut or eliminate the program but advisors warn that a change would increase the rate of uninsured children. Jason Millman, *Washington Post*, Sept. 9, 2014

*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 student Rachel A. Polzin (JD/MHA anticipated May 2015) and Kalle Deyette (JD/MPH anticipated May 2016).*

## Consumers Turn to Online Auction Site for Cheaper Medical Care

As many Americans use the Internet to book hotels and flights and even search for a mate, some are now starting to go online to arrange medical care through an auction website called *Medibid*. Operating largely outside the confines of traditional health insurance, the four-year-old online service links patients seeking non-emergency care with physicians and facilities that offer what they need. To date, approximately 120,000 consumers or "seekers" have used *Medibid* and roughly 6,000 doctors, surgery centers and even some hospitals have registered as "bidders". The founder of *Medibid* contends that offering this type of service in the U.S. is long overdue and describes it as "disruptive innovation" that introduces transparency and competition.

The way *Medibid* works is seekers post requests for services on the website ($25/request or $60 for unlimited/year), wait for physicians to bid ($50/bid or $250/many) and once the seekers accept a bid, *Medibid* bows out and patients and physicians finalize the arrangement. Many bids are package deals that include the professional charge, facility fee and anesthesia services, yet complications are rarely covered under the terms of *Medibid*.

Despite lower prices, this unconventional option is not without its critics. A professor of surgery at John Hopkins Hospital expressed concern over the lack of good quality metrics and asks, "How do you know what you're getting?" *Medibid* does not verify credentials; rather physicians are required to send their license number to patients, who then have the option of checking the physician on their own through third-party services.

The head of the division of bioethics at NYU Langone Medical Center has similar concerns related to the lack of oversight in free-standing surgery centers, where many of *Medibid* services are performed. Compared to hospitals, these settings typically have to comply with lighter regulations, have fewer patient safeguards in place, and are often exempt from quality reporting requirements. Additionally, the lack of peer review is unsettling in that "it doesn't take a lot of qualifications to open one." Sandra G. Boodman, *The Washington Post*, Aug. 4, 2014
http://www.washingtonpost.com/national/health-science/like-priceline-for-patients-doctors-compete-for-business-via-online-bids-for-surgery/2014/08/01/030d3576-f7e4-11e3-a606-946fd632f9f1_story.html

**Medicare Offers Settlement to End Battle Over Hospitals' Claim Appeals**

Facing an 18-month backlog of an estimated 800,000 cases, Medicare recently—and quietly—offered to settle thousands of hospital appeals related to short-term care. The appeals stem from a disagreement over billing, where Medicare and its private audit contractors believe hospitals are inappropriately billing outpatient, short-stay care at the much higher inpatient rate. The difference between the inpatient and outpatient rate can add up to thousands of dollars per patient and hospitals argue they are correctly billing short-term stays at the inpatient rate.

The disagreement has led to a stalemate between Medicare and hospitals and a lengthy wait before administrative law judges can hear cases. The proposed settlement has been described as an opportunity for hospitals to "alleviate the administrative burden of current appeals on both the hospital and the Medicare system" and could total several hundred million dollars. Hospitals have two months to decide whether to take the settlement, which would pay sixty-eight cents for every dollar billed and Medicare says it will pay them within sixty days of when they reach an agreement.

Congress and industry leaders recently denounced Medicare's lengthy delays in appealing claims. Thus, the proposed settlement represents considerable concession by Medicare, which has also been praised for "taking a big step forward to get[ing] rid of a major problem." Yet, the settlement offer has generated mixed reviews from hospitals. Ultimately, hospitals will have to decide on whether they want to gamble on getting paid in full, or take the deal while it is still on the table. Reed Abelson, *New York Times*, Aug. 29, 2014 [http://www.nytimes.com/2014/08/30/business/medicare-will-settle-appeals-of-short-term-care-bills.html](http://www.nytimes.com/2014/08/30/business/medicare-will-settle-appeals-of-short-term-care-bills.html)

## Congress Urged to 'Catch Up With Technology' and Revamp Legislation

At a senate roundtable entitled, "Harnessing the Power of Telehealth: Promises and Challenges," participants identified reimbursement and licensure as key impediments to getting telehealth services to those who might benefit.

Under current reimbursement, Medicare only permits payment for telehealth services in rural areas or ones with rural characteristics. Problems arise in that many areas in the country do not meet the regulatory definition of rural, but are still underserved by specialists. CMS officials noted, "There has been significant innovation since implementation of the agency's telemedicine restrictions," which supported the roundtable moderator's call for Congressional bipartisan action to ensure telemedicine laws "catch up with technology."

Medical licensure was also highlighted as an impediment. The current licensure laws create obstacles for telehealth by requiring the remote consulting physician be licensed in the state where the patient is located. Several options have been set forth to address this problem, such as the Federation of State Medical Boards' proposed Interstate Licensure Compact, where physicians would have a streamlined licensing process in states that adopt the compact. A member of the American Medical Association Board of Trustees said that "organized medicine" supports the licensure compact and wants it to move forward.

Yet, the AMA also warns that potential safety threats associated with telemedicine still loom, such as prescribing antibiotics without appropriate diagnostics testing. Mindy Yochelson, *BNA's Health Care Daily Report*, Sept. 16, 2014 http://www.bloomberglaw.com/search/results/c6334dec07d086a539f11365db0cac92/document/X13PKVSS000000?search32=C9P6UQR5E9FN6PB1E9HMGNRKCLP6QFAND5Q6SPBJEDIN682JC5SI0JB5CHKM6OBICKG4IRBGCLI6ASP085H6IR39EHSJMEREDTFMIRBGBTO6GSJ1EDIN6F9H7CTMCQBOBTH6URRCBTONAPBIFh

### FDA Encouraged to Limit Male Use of the 'Foundation of Youth'

An expert panel recently voted 19-1 for the FDA to impose strict new limitations on testosterone drugs—a multibillion-dollar industry. Medical experts became concerned when what was once only taken to treat serious medical conditions turned into a drug that over two million American men are taking. The significant increase is driven in part by marketing that suggests the drugs are a solution for low energy, low libido and other ills, many of which are simply the result of aging. Since the early 2000s, testosterone usage by men in their 40s has quadrupled, reflecting what has been described as "people looking for the fountain of youth."

Experts also point to the vagueness in testosterone drug labels as being a critical problem because many physicians interpret them to include *any* man with low testosterone, but even then, a fifth to a quarter of men who are prescribed the drug have not had a baseline test of their testosterone level. Even more concerning is the lack of research on the effects of using the drug, which has led frustrated experts to ask why the F.D.A. allowed the "push for the creation and selling of 'aging is optional for men,'" especially when any benefit and potential harm in using it are unknown.

If the FDA adopts the panel's recommendations, it could significantly reduce the number of men prescribed the drugs, by limiting the label to men with serious medical conditions such as pituitary gland problems. The panel also voted to give the FDA more control over the marketing of the drugs, allowing the agency to draw a narrower definition of whom drug companies could target. The panel's primary aim was to "rein in the inappropriate advertising and use of [testosterone] drugs" and although the F.D.A. often takes the advice of such panels, changes will ultimately be up to the discretion of the agency. Sabrina Tavernise, *The New York Times*, Sept. 17, 2014 http://www.nytimes.com/2014/09/18/health/testosterone-drugs-fda.html?_r=0

## RACs Recover for Medicare

Medicare's recovery auditor contractors, or RACs, found $3.75 billion of incorrect payments, almost all related to overpayments, made to doctors and hospitals in the fiscal year of 2013. Providers who appealed these audits won less than 20 percent of the time. RACs resulted in $3 billion going back into Medicare's trust fund, as RACs receive between nine percent and 12.5 percent of improper payments they find. While the RAC trade group and lobbying arm, the American Coalition for Healthcare Claims Integrity, feels this report shows the success of the RAC program, the health care industry said the figures are distorted. American Hospital Association data on RACs stated that in the first quarter of 2014 hospitals won 66 percent of their appeals of the RAC denials. The data also says hospitals appealed 50 percent of the denials. An attorney from Hall Render said hospitals generally have a good success rate in RAC appeals.

Part of the differences between what the two groups say may stem from the fact that the government may count appealed claims multiple times, based on decisions at different levels of appeals, while the AHA only reports final decisions from Medicare's appeals courts. Additionally, the RAC report sheds an interesting light on the CMS appeals settlement process, where hospitals have until the end of October to accept an offer of the government reimbursing 68 percent of their backlogged claims if they withdrew all of their appeals, which seems like a particularly favorable settlement if hospitals were winning under 20 percent of appeals. Bob Herman, *Modern Healthcare*, Sept. 29, 2014 [http://www.modernhealthcare.com/article/20140929/NEWS/309299939](http://www.modernhealthcare.com/article/20140929/NEWS/309299939),

## More Hospitals Will Face Medicare Payment Reductions for Hospital Readmission at Higher Penalties

Medicare will fine a record number of hospitals for too many readmissions. Records show that 2,610 hospitals will receive a reduction in Medicare payments ranging from one-hundredth of a percent to three percent of Medicare payments, with an average reduction of 0.63 percent. This represents three-quarters of the hospitals subjected to the Hospital Readmission Reductions Program.

Under the Hospital Readmission Reduction Program, the Centers for Medicare and Medicaid Services (CMS) may reduce a hospital's payments if too many of the hospital's Medicare patients return within a month time period for additional treatments after initially being admitted for an elective knee or hip replacement, lung ailments such as chronic bronchitis, heart failure, heart attacks or pneumonia. A hospital may be fined if readmission rates for any category of illness are above the national standard set by CMS. The penalty may be as high as a three percent reduction in payments for every Medicare patient the hospital sees the following year regardless of whether the patient is readmitted. The maximum penalty was raised from two percent last year and has reached the maximum the law provides.

These penalties are changing hospitals and administers' attitudes and behaviors. Some hospitals now report that they will do their best to care for returning patients without readmitting them as overnight patients, and thus avoid CMS, including the patient within its readmission rates. Others report assign nurses or pay private companies to visit patients at home to ensure the patient is following his or her discharge plan.
Jordan Rau, *Kaiser Health News*, Oct. 2, 2014
http://www.kaiserhealthnews.org/Stories/2014/October/02/Medicare-readmissions-penalties-2015.aspx?utm_source=khn&utm_medium=internal&utm_campaign=searched.

### U.S. Doctors and Teaching Hospitals Were Paid $3.5 Billion from Drug and Device Makers. However, Concerns regarding the Data's Accuracy Remain.

The Sunshine Act, which was passed as part of the Patient Protection and Affordability Care Act (ACA), requires all drug and medical device manufactures to report payments or transfers of value made to providers and teaching hospitals. The Act's intention is to protect the integrity of medical judgment and research by making conflict of interests more transparent. The first round of data was disclosed by the Center for Medicare and Medicaid Services (CMS) on Sept. 30, 2014 and covered the five-month period from Aug. to Dec. 2013. The disclosures revealed that 4.4 million payments were made to approximately 550,000 doctors and 1,360 teaching hospitals totaling $3.5 billion.
Questions remain about the accuracy and usefulness of the data. First, the data include only five months of data and have no historical comparisons. Second, about 40 percent of the records released were "de-identified," removing the name of the physician or hospital the payment was made to. Without identifying the payment recipient, it is impossible to assess the conflict of interest and whether the payment unduly influenced the provider or hospital. Conflicts of interest need to be evaluated based on the totality of circumstances. Third, some physicians found payments were wrongly or unfairly attributed to them.

In addition, the roll out of the disclosure faced technical issues. Drug companies had trouble uploading data to the government's servers. In addition, the database was suspended for twelve days after CMS discovered that manufacturers were submitting intermingled data. For example, manufacturers would mix-up the wrong national provider identifier (NPI) number for physicians with the same first and last names. Despite the technical issues, Pharmaceutical Research and Manufacturers of America (PhRMA) continues to support the Sunshine Act and pledges to work diligently to ensure accuracy and timely submission of data. It does ask for additional guidance from CMS in clarifying the reporting regulations. Bronwyn Mixter, Sept. 19, 2014 https://www.bloomberglaw.com/search/results/436fcc2ceeed13617e82df448ebca4f4/document/X6R1DNAS000000?search32=C9P6UQR5E9FN6PB1E9HMGNRKCLP6QFAJELN76Q39DPII0GB3EGTJMRJFBTKMQS2VE1K74OBJCLPJQC9R7DJ6IU2VC9NMUR2VE5QMASJP7KOG. Caroline Chen, Drug, Oct. 06, 2014, available at https://www.bloomberglaw.com/search/results/436fcc2ceeed13617e82df448ebca4f4/document/X32NG2N8000000?search32=C9P6UQR5E9FN6PB1E9HMGNRKCLP6QFAJELN76Q39DPII0GB3EGTJMRJFBTKMQS2VE1K74OBJCLPJQC9R7DJ6IU2VC9NMUR2VE5QMASJP7KOG.

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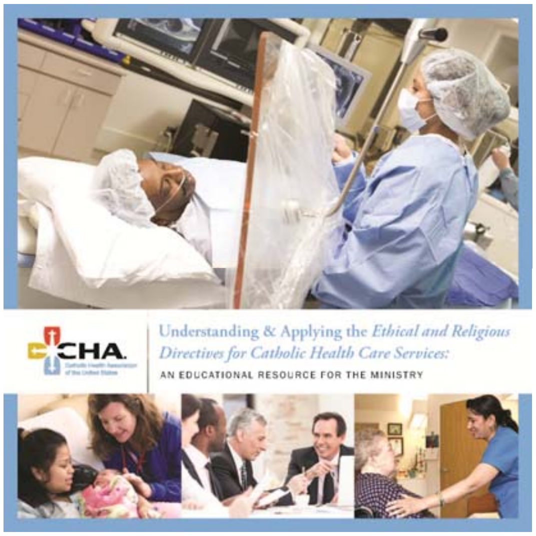

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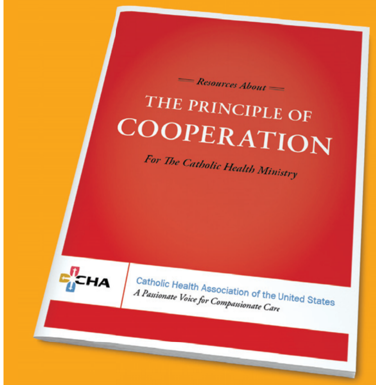

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