# Health Care Ethics USA

### A resource for the Catholic health ministry

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### A Christian Ethic of Immigration

Kristin E. Heyer, Ph.D.
Bernard J. Hanley Professor
Department of Religious Studies
Santa Clara University
Santa Clara, Calif.

#### Introduction

On July 8, during his first official trip outside Rome since his election, Pope Francis celebrated mass on Lampedusa, an island in the southern Mediterranean that has become a safe haven for African migrants seeking passage to Europe. 1 He chose this site after the suffering of migrants who had recently died at sea while attempting to cross from North Africa revisited him like "a thorn in the heart." Investments of penitential violet, the pope celebrated mass within sight of the "graveyard of wrecks," where fishing boats carrying migrants and asylum seekers end up after they drift ashore. He repented in his homily for the cruelty present in us all and in "those who anonymously make socio-economic decisions that open the way to tragedies like this," lamenting a "globalization of indifference." His powerful witness made visible the cost of migration often occluded in our own context as well, where migrants die trying to cross the increasingly fortified U.S.-Mexico border. The death toll of migrants crossing the deserts of Arizona has steadily mounted even as crossings decline.

Ten years ago the U.S. and Mexican bishops urged both nations to address root causes of and legal avenues for migration and to safeguard family unity in their pastoral letter, "Strangers No Longer: Together on the Journey of Hope." By contrast, border enforcement has remained the primary focus for so many, issuing dehumanizing consequences for undocumented migrants and deepened divisions within communities. The consequent deportation-by-attrition practices and removal quotas along with the growth of the "immigration industrial complex"2 have nevertheless failed to resolve the problem of a significant undocumented presence within the United States or the need for Mexican and other migrants to enter its borders. The global phenomenon of human mobility has only intensified: today, one person in nine lives in a country where international migrants comprise one-tenth or more of the total population.<sup>3</sup>

Amid this shifting milieu marked by new fears, along with more timeless reservations regarding power and security, the immigration debate in the U.S. context has been framed in terms that distract from actual motives and consequences for migrants and

communities. Contemporary congressional debates about how to address the cultural and economic impact of the estimated 11 million undocumented immigrants residing in the United States continue to reflect a market logic, xenophobic fears, and indifference to vulnerable populations. By contrast the centrality of human life and dignity in the Catholic tradition challenges death-dealing policies and practices.

Mounting border deaths and policies that compel and then punish irregular migration are profoundly at odds with Catholic commitments. In particular, the tradition's understanding of human rights, the political community, and the universal destination of created goods squarely challenge the persistent reality that the vast majority of contributing and vulnerable migrants remain excluded from a viable, timely path to citizenship and its protections.<sup>4</sup>

#### Scripture and Immigration

To what do the demands of discipleship call Catholics amid these human realities at our borders, in our fields, and within our parish and civic communities? How might Christian ethics inform our reflection on the health care needs and barriers facing undocumented immigrant populations? The Christian faith brings rich resources to bear on the complicated questions of immigration. The formative liberation of Israel by God from enslavement by the Egyptians led to commandments regarding hospitality to strangers (Ex 23:9; Lv 19:33). Indeed,

after the commandment to worship one God, no moral imperative is repeated more frequently in the Old Testament than the command to care for the stranger. When Joseph, Mary, and Jesus fled to Egypt, the émigré Holy Family became the archetype for every refugee family. In Jesus' parables such as the Good Samaritan (Lk 10:25-37) and the Last Judgment (Mt 25:31-46), he identified love of neighbor and just living with care for the vulnerable stranger among us.

This centrality of love of neighbor does not reduce the immigration paradigm to charity or largesse, or move it out of the inclusive civic conversation. Rather it enjoins justice. This summons does not circumvent basic fairness, which is already in short supply; the United States accepts their labor, taxes, and purchasing power, yet does not offer undocumented migrants the protection of its laws.<sup>5</sup> As the signs of our times attest, undocumented immigrants encounter legion examples of distributive, commutative, structural, and even legal injustice, which the Catholic tradition bids citizens to resist and redress. For example, the widespread exploitation of undocumented day laborers violates fundamental fairness in exchange (commutative justice). The regional juxtaposition of relative luxury and misery while basic needs go unmet challenges basic notions of distributive justice. The asymmetry and impact of free trade agreements and utterly outmoded visa policies impede rather than empower persons' active participation in societal life (social justice).

With a recollection of biblical narratives that recount humans' experience of God's hospitality, of our own being as gift (and ancestry as immigrant), we are called to restore the covenant in turn. Becoming neighbor enjoins not only compassion but also liberation. For just as the Good Samaritan promises additional recompense to the innkeeper, Christians are called to enter the world of the neighbor and "leave it in such a way that the neighbor is given freedom along with the very help that is offered."6 The "unfreedom" of present and would-be migrants pointedly illustrates the urgency of this responsibility. In the contemporary U.S. context, this lack of freedom immigrants experience fundamentally stems from their exclusion from membership in civic society. Undocumented immigrants remain deprived of the primary good of membership, or the "right to have rights." 7

#### The Catholic Social Tradition— Human Dignity, Rights, and the Common Good

A Catholic immigration ethic is grounded not only in a scriptural heritage but also in its vision of the person as inherently sacred and made for community. In the Catholic tradition, a person imaged in a relational, Trinitarian God is endowed with human rights understood not as absolute claims made by radically autonomous individuals, but rather, claims to goods necessary for each person to participate with dignity in society's communal life. Thus whereas a Christian anthropology does not compromise autonomy, it understands humans as profoundly relational and interdependent.

Flowing from this vision, Catholic principles of economic and migration ethics protect not only civil and political rights, but also more robust social and economic rights and responsibilities. This understanding of human rights and the nature of the political community ground a defense of twin rights to emigration and immigration that generally privileges reception over exclusion. The Catholic tradition's affirmation of social and economic rights establishes persons' rights not to migrate (fulfill those rights in their homeland) and to migrate (if they cannot support themselves or their families in their country of origin).9 The state's purpose is to protect the common good of its citizens, and when the common good remains so distant from attainment that a population is deprived of basic human rights, people may seek a new home elsewhere.

Once migrants do seek life in new lands under such circumstances, a Catholic anthropology profoundly critiques patterns wherein stable receiving countries accept the labor of millions of immigrants without offering legal protections or viable paths to citizenship. Such "shadow" societies risk the creation of a permanent underclass, harming both human dignity and the common good. From Pope Leo XIII's 1891 warnings that neither human nor divine laws permit employers to exploit for profit another's need, to Pope Francis' recent condemnations of global economic practices that are rooted in idolatry and profit off of human need, the protection of human dignity remains the central criterion of economic justice. The encyclical tradition makes clear that "every

economic decision and institution must be judged in light of whether it protects or undermines the dignity of the human person . . . realized in community with others." <sup>10</sup> In *Laborem exercens*, for example, Pope John Paul II roots his condemnation of the social and financial exploitation of migrant workers in the principle that ". . . the hierarchy of values and the profound meaning of work itself require that capital should be at the service of labor and not labor at the service of capital." <sup>11</sup>

Hence the Catholic social tradition explicitly protects the basic human rights of undocumented migrants in host countries in light of longstanding teachings on human and workers' rights, which do not depend on citizenship status.12 The tradition promotes rights to just wages, benefits, safe working conditions, and health care assistance, especially in the case of on-the-job injuries, and rights to association.<sup>13</sup> Within the U.S. labor market, the pervasive exploitation of undocumented immigrants in terms of substandard wages and protections, disproportionately unsafe conditions, wage theft, and a lack of mechanisms to enforce humane protections thus constitute basic violations.14 Offering unauthorized immigrant laborers and their family members a viable path to legalization remains the best hope for countering this pervasive exploitation in an effective and enduring way. At the same time, such avenues would provide stability and augment productivity in the workforce and potentially serve public health ends. 15

Beyond its foundation in the social and economic rights flowing from a relational anthropology, the Catholic right to migrate is also rooted in the universal destination of created goods. As the tradition holds, state sovereignty "cannot be exaggerated" to the point that access to land is denied to needy people from other nations, provided that the national common good "rightly understood" does not forbid it.16 Flowing from the understanding of rights articulated above and this notion of the goods of creation, a key component of the Catholic right to migrate remains its inclusion of economic rights violations alongside political oppression as legitimate causal factors.<sup>17</sup> While the social tradition recognizes the right of sovereign nations to control their borders, the right is not understood to be absolute in nature.

Contemporary push factors continuing to drive much of the immigration to the United States and the treatment of the undocumented within its borders threaten the common good. The Catholic recognition of both the right of sovereign nations to control their borders and its temperance by conditions of social justice and the universal destination of created goods continue to warrant citizenship rights for many who remain within the United States without viable avenues to pursue this basic right and responsibility. Given the role the United States has played in shaping conditions that directly contribute to irregular migration and its relative ability to absorb newcomers into its communities and economy, it has a particular obligation to the reception and

accommodation the Catholic social tradition urges.<sup>18</sup>

With more than 60 percent of undocumented immigrants in the United States having lived here for over ten years, over 16.5 million U.S. households home to mixed-status families, and 2 million undocumented students in primary and secondary schools across the country, a "double society" increasingly threatens the common good, ". . . one visible with rights and one invisible without rights—a voiceless underground of undocumented persons."19 The legalization of eligible immigrants serves the ends of proportionate security in addition to human rights protections. Bringing unauthorized immigrants out of the shadows by means of opportunities to meet certain conditions and regularize their status would allow the U.S. government to account for its society's members and focus enforcement efforts on genuine security threats. Continuing to disallow viable paths to legalization for the majority of immigrants welcomed in the marketplace but not the voting booth, college campus, department of motor vehicles, or stable workplace risks making permanent this underclass of disenfranchised persons, undermining not only Christian commitments but also significant civic values and interests.

Finally, a Catholic theory of nationality calls for new immigrants (as all community members) to concretely contribute to dignified life in the community of all—demonstrating solidarity with their fellow residents and

contributing to society. Rather than fearfully navigating in the shadows or hitting the "ceiling" of high school or rare college scholarships, a path to legalization would allow immigrants to work, advance in their studies, and to secure basic health services and police protection, thereby furthering the good of all. In the Catholic tradition, rights fundamentally secure participation in the life of the community, and imply correlative responsibilities. Hence the Catholic vision of the person and its consequent rights and responsibilities—civil, political, economic, social, cultural, and religious in nature confer not only rights of protection in one's homeland, migration where these remain unrealized, reception and dignified conditions in countries of destination, but also meaningful participation in the life of one's new community.

#### Conclusion

Whereas a Christian immigration ethic requires more than a policy response, it necessarily entails attention to the politically possible in light of the stakes of ongoing suffering. At a concrete level, justice requires, negatively, that countries refrain from creating or substantially contributing to situations that compel people to emigrate and that host countries refrain from exploiting or extorting undocumented laborers. Positively, receiving immigrants fleeing situations of dire economic need, offering citizenship protections to those they do employ, and developing policies that reflect actual labor needs and hiring practices and protect family unity are obligations in justice.

Given these demands of justice, the United States has obligations to redress its role in abetting irregular migration and to offer those who live and work within its borders a viable path to earned legalization. Care must be taken that reform efforts not accomplish greater justice for new immigrants at the expense of low-wage native-born workers. Solutions that "raise the floor" for all workers must be sought. Just as our repeated failure to pass the DREAM act betrays a lack of recognition of the connection between children and families' well-being and the wider social order, the exclusion of immigrants from health care that is truly accessible threatens the common good.

An approach rooted in Catholic commitments must both reduce the need to migrate and protect those who find themselves compelled to do so as a last resort. Safeguarding justice and compassion for immigrants will require commitment over the long haul, regardless of what transpires on Capitol Hill this year.

traded companies since 1998. For a genealogy of "immigration industrial complex," which alludes to the conflation of national security with immigration law enforcement and "the confluence of public and private sector interests in the criminalization of undocumented migration, immigration law enforcement, and the promotion of 'anti-illegal' rhetoric," see Tanya Golash-Boza, "The Immigration Industrial Complex: Why We Enforce Immigration Policies Destined to Fail" *Sociology Compass* 3.2 (Feb 2009): 295–309 at 295ff.

<sup>3</sup> Forty years ago, the ratio was 1:29; see Aaron Terrazas, *Migration and Development: Policy Perspectives from the United States* (Washington, D.C.: Migration Policy Institute, 2011): 1; available at:

http://www.migrationpolicy.org/pubs/migdevpolic y-2011.pdf (accessed July 17, 2012).

<sup>4</sup> Pope Pius XII, Exsul familia (On the Spiritual Care to Migrants) (August 1, 1952) in The Church's Magna Charta for Migrants, ed. Giulivo Tessarolo, PSCC (Staten Island, N.Y.: St. Charles Seminary, 1962); Pope John XXIII, Pacem in terris (April 11, 1963)

http://www.vatican.va/holy father/john xxiii/ency clicals/documents/hf j-

xxiii enc 11041963 pacem en.html; Pope Paul VI, *Populorum progressio* (March 26, 1967) <a href="http://www.vatican.va/holy-father/paul-vi/encyclicals/documents/hf-p-">http://www.vatican.va/holy-father/paul-vi/encyclicals/documents/hf-p-</a>

vi enc 26031967 populorum en.html; Second Vatican Council, *Gaudium et spes*, 69, 71 see also Catechism of Catholic Church, 2402. (URLs accessed July 17, 2012).

<sup>5</sup> Cardinal Roger Mahony, "For Goodness Sake: Why America Needs Immigration Reform," *The Tidings* 2004 (February 11, 2011).

<sup>6</sup> John R. Donahue, *The Gospel in Parable* (Philadelphia: Fortress Press, 1988), 133.

<sup>7</sup> See Hannah Arendt, *The Origins of Totalitarianism* (New York: Harcourt, Brace & World, 1966), chapter 9.

<sup>8</sup> Michael J. Himes and Kenneth R. Himes, Fullness of Faith: The Public Significance of Theology (New York: Paulist Press, 1993), 46.

<sup>&</sup>lt;sup>1</sup> Portions of this article appeared in Kristin E. Heyer, *Kinship Across Borders: A Christian Ethic of Immigration* (Washington, D.C.: Georgetown University Press, 2012) and are reprinted with permission. Other sections are adapted from "Legalization and the Undocumented According to Catholic Social Teaching," in Todd Scribner and Kevin Appleby, eds., *On 'Strangers No Longer': Perspectives on the Historic U.S.-Mexican Bishops' Pastoral Letter on Migration* (Mahwah, NJ: Paulist Press, 2013).

<sup>&</sup>lt;sup>2</sup> Whereas in the United States private companies control nearly half of total detention beds and 7 of 11 British detention centers are run by for-profit contractors, Australia has entirely outsourced its enforcement to a succession of three publicly

<sup>&</sup>lt;sup>9</sup> See Pope John XXIII, *Pacem in terris* (April 11, 1963) no. 106. See also United States Conference of Catholic Bishops and *Conferencia del Episcopado* 

*Mexicano*, "Strangers No Longer: Together on the Journey of Hope" (Washington, D.C.: USCCB, 2003) no. 34-5.

<sup>10</sup> National Council of Catholic Bishops, "Economic Justice for All: Pastoral Letter on Catholic Social Teaching and the U.S. Economy Issued by the National Conference of Catholic Bishops, November 13, 1986" (Washington, D.C.: the United States Conference of Catholic Bishops Inc., 1986), nos. 1, 14.

<sup>11</sup> Pope John Paul II, Laborem exercens, no. 23. 12 Pope John Paul II's Ecclesia in America "reiterates the rights of migrants and their families and the respect for human dignity 'even in cases of non-legal immigration," Ecclesia in America (Washington, D.C.: USCCB, 1999), no. 65. Over recent decades social encyclicals have enumerated migrant rights to life and a means of livelihood; decent housing; education of their children; humane working conditions; public profession of religion; and to have such rights recognized and respected by host of government policies. See 1969 Vatican Instruction on Pastoral Care (no. 7); 1978 Letter to Episcopal Conferences from the Pontifical Commission for the Pastoral Care of Migrant and Itinerant peoples (no. 3); Pope Paul VI, Octogesima adveniens (no. 17); Pope John XIII, Pacem en terris (no. 106); National Council of Catholic Bishops, Resolution on the Pastoral Concern of the Church for People on the Move (Washington, D.C.: USCC,

<sup>13</sup> Pope John Paul II, *Laborem exercens*, no. 19-20. <sup>14</sup> For an analysis of day labor abuses in terms of Catholic social thought and social sin, see Kristin Heyer, "Strangers in Our Midst: Day Laborers and Just Immigration Reform," *Political Theology* 9, no. 4 (2008): 425-53.

1976) and endorsed by Pope Paul VI; and

"Strangers No Longer," no 38.

<sup>15</sup> Donald Kerwin and Charles Wheeler, "The Case for Legalization, Lessons from 1986, Recommendations for the Future." This article originally appeared in *Issues in Immigration*, Vol. 1 (Center for Migration Studies, 2004). It was reprinted by *Bender's Immigration Bulletin*, Vol. 12, No. 3 (Feb. 1, 2007).

<sup>16</sup> Exsul Familia introduction and Pacem in terris, no. 106.

<sup>17</sup> The 1969 *Instruction on Pastoral Care* asserts that "where a state which suffers from poverty

combined with great population cannot supply such use of goods to its inhabitants...people possess a right to emigrate, to select a new home in foreign lands and to seek conditions of life worthy of man." Sacred Congregation for Bishops, Instruction on Pastoral Care, no. 14. For a helpful discussion of Catholic teaching on economic refugees, see Drew Christiansen, "Sacrament of Unity: Ethical Issues in the Pastoral Care of Migrants and Refugees," in Office of Pastoral Care of Migrants and Refugees, Bishops' Committee on Migration, National Conference of Catholic Bishops, Today's Immigrants and Refugees: A Christian Understanding (Washington, D.C.: United States Catholic Conference, 1988), 81-114 at 90-1.

<sup>18</sup> "Strangers no Longer," no. 36.

<sup>19</sup> National Conference of Catholic Bishops, Together a New People, Pastoral Statement on Migration and Refugees, November 8, 1986, p.10.

## Health Care for Our Immigrant Neighbors: The Need for Justice and Hospitality

Mark Kuczewski, Ph.D.
Professor, Medical Ethics
Loyola University Stritch School of Medicine
Maywood, Ill.
mkuczew@lumc.edu

Trisha Cassidy, MBA Sr. Vice President and Chief Strategy Officer Alexian Brothers Health System Arlington Heights, Ill. patricia.cassidy@alexian.net

#### Introduction

We are in an exciting and challenging time in U.S. history regarding health care. The same is true regarding policy-making and attitudes toward immigration to the United States. In combination, the two issues are volatile, almost combustible. For instance, many will recall the infamous taunt of "You lie!" that Representative Joe Wilson (R-SC) hurled at President Obama during the 2009 address on health-care reform to a joint session of Congress. This outburst was, of course, in response to the President's assertion that undocumented immigrants would be excluded from any new health-care coverage legislation (which became the Affordable Care Act).

It is very unfortunate that these two issues have become intertwined. There is no intrinsic connection between the two. We believe that insuring and treating all who live within a community would serve all well and should be the norm. Health care is similar to

basic education in that it is a basic good and should be delivered to those in need of it without regard to accidental circumstances such as immigration status. To do so benefits the community as a whole and failing to do so harms the community.

It seems that some if not much of our public dialogue regarding the insuring and provision of health care to all has been distorted by uninformed and selfish, perhaps even sinful, attitudes. In this fallen state of affairs, how should Catholic health-care institutions respond? We will argue that Catholic moral anthropology provides a corrective lens through which to view the issue of immigration. This lens focuses us on how we can enable our immigrant neighbors to contribute to the community and foster their full participation. When viewed in this way, Catholic health care is called to a leadership role both in terms of advocacy for more just public policies and also to directly and

humanely, i.e., hospitably, serve immigrant populations in our communities.

### Uninformed Stereotypes and Sinful Attitudes Concerning Immigrants

Public policy discourse today is sometimes framed in divisive terms that pre-empt the development of a consensus inclined toward the common good. While this is not true of all who have concerns about immigration reform, it does seem to be the case for some if not many. The latest false dichotomy to gain traction is the rhetoric of "makers v. takers." This rhetoric suggests that some people are intrinsically producers of goods and services, while others are parasites trying to unfairly take what rightfully belongs to the producers. We routinely hear people espouse stereotypes regarding immigrants that are derivative and reflective of this worldview.

- "They take our jobs."
- "They are free loaders," "They come here for welfare," or "for health care," "education," or other "handouts."
- "They won't learn English" or in other ways, refuse to assimilate.
- "They are law breakers and we mustn't reward them."

The conclusion of this kind of thinking is that immigrants are ungrateful thieves, takers who take what does not belong to them. They are the "undeserving" poor.

While such stereotypes might sound like the pet biases of armchair Archie Bunkers, we must realize that they are often the assumptions behind many legislative proposals that have significant traction in our policymaking process. These proposals include a focus on border security, detention,

deportation and denying a path to citizenship for undocumented immigrants. (Of course, it is also the case that some of those advancing these and similar proposals are doing so on the basis of other assumptions and legitimate concerns). Furthermore, the Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA) of 1996, colloquially known as "welfare reform," embraced the premise that immigrants should not be eligible for important benefits until they have been in the U.S. with authorization for at least five years.

These problematic assumptions may have had an impact on health care reform as well. In order to gain passage, the Affordable Care Act's expansion of Medicaid did not change the PRWORA five-year exclusion of immigrants who are here with full governmental authorization. Furthermore, all unauthorized immigrants remain ineligible for federally funded health care, including the new subsides to buy insurance, and are even disqualified from purchasing a full-price health insurance policy with their own money on a federal or state exchange. Even DREAMers (i.e., adult undocumented immigrants who were brought to the U.S. as children) who have received a two-year authorization to work within the United States through the Deferred Action for Childhood Arrivals program of the U.S. Citizenship and Immigration Services are ineligible to so purchase health insurance (see Table A.)

This stereotype-based approach to insurance coverage has several obvious consequences. Chief among them is that immigrants will often continue to be uninsured. As the total

number of the uninsured decreases substantially, immigrants will become a larger portion of the uninsured. As a result, immigrants are increasingly likely to be targeted by inhumane strategies in order to reduce uncompensated costs. Perhaps chief among these are forced "medical repatriation" in which chronically ill or even terminally ill patients are essentially deported against their will by a health care facility as a discharge plan. Similarly, as most hospitals must examine and stabilize any presenting patient before transfer by virtue of the Emergency Medical Treatment and Active Labor Act (EMTALA), some prominent critics such as former Florida Governor Jeb Bush, have proposed that the United States allow states to delineate their own particular limits on EMTALA-related services, potentially closing the ER door as a point of access to care for this population. It is easy to show that on basic principles of the mission and values of health-care institutions, such proposals should be non-starters. Moreover, a view of the human person informed by the richness of the Catholic philosophical and theological traditions would reject, at their roots, the negative assumptions about our immigrant neighbors.

### A Catholic Social Justice Response: Moral Anthropology & Policy

In several different teaching documents, Pope John Paul II and the Conferences of Catholic Bishops of both the United States and Mexico outlined the knowledge and attitudes that Christians should bring to discussions about immigration.<sup>4</sup> There is no shortage of studies to show that the attitudes described earlier are uninformed and empirically wrong.<sup>5</sup> But empirical studies are often received or rejected

based on the predispositions and view of human nature that the listener holds. Furthermore, human motivations are not mere whims that can easily be influenced by studies and surveys. In any case, a Catholic view of human nature provides an alternative perspective to the one described above and ought to inform the imaginations of Catholics as they assess the immigration laws of the United States and urge reform.

The Catholic view of human beings that emerged in the 20<sup>th</sup> century highlights a number of key features of human nature. In many ways, these features are and should be obvious to common sense and observation. Human nature is manifest in our experience, not something hidden and esoteric. The following are some of those elements relevant to this discussion.

Catholics believe in the intrinsic value of each person. We sometimes refer to this as human dignity in its original Latin meaning of "worth." So, while governments have a right to promote secure borders, they cannot simply disregard the effects of such policies on human beings who are not their citizens.

On a Catholic view of human nature, people are laboring creatures. We work. We work in order that by our labor we might provide sustenance for ourselves and our families. But we also work as an expression of creative natures. Thus, Catholic social teaching speaks of the dignity of labor. There is not a distinction between makers and takers in Catholic moral anthropology. We are all inclined to be makers. In addition, the relationship between a worker and an employer is not sacrosanct and inviolable. If that relationship does not respect the dignity

of labor by enabling the worker to earn a living wage and to have sufficient leisure to restore his body and to engage in social activity such as raising a family, the government, by virtue of its duty to promote the common good, should promote more just arrangements. 6

Based on this view of human nature, Catholic social teaching simply rejects anti-immigrant sentiment. We must respect our neighbors and their cultures. We cannot hide behind a self-righteousness premised on a false sense of cultural superiority. The magisterium has made clear that culture is an important part of human nature and a way in which our relationship to God and each other is mediated.<sup>7</sup> Thus, we must not demand a forced homogenization of our neighbors into our cultural norms.

### Implications for Health Care Facilities and Health Care

Respecting human nature has a variety of implications both for the clinical delivery of health care and for our role as a ministry that advocates for the underserved. The view of human nature that Catholic social teaching highlights requires that institutions respond to human need. The Ethical and Religious Directives are clear about this: "A Catholic health care institutional service is a community that provides health care to those in need of it. This service must be animated by the Gospel of Jesus Christ and guided by the moral tradition of the Church."8 Those needs require that we be welcoming institutions that care for our community and its members.

Catholic health-care institutions must present themselves as welcoming places, places of hospitality.9 Hospitality is rooted in our moral mission and also our pragmatism. Hospitals want the sick to present while their illnesses are in a treatable stage and early enough to minimize the spread of contagion in the community. Practices such as forced medical repatriation must be renounced because they undermine such goals. 10 Hospitality requires promoting practices that are culturally welcoming and medically efficacious. The next section provides examples of how this imperative applies to the new market opportunities brought to us by the Affordable Care Act.

With respect to advocacy, Catholic health care must support other Church ministries in advocating for humane and comprehensive immigration reform. 11 A Catholic view of human nature enables us to look beyond a selfish view of health insurance as a benefit that immigrants are trying to steal. We are able to view health insurance as a community good that fosters the effective participation of all in the community. Federal subsidies to assist a person to purchase insurance enable the person to make a monetary contribution to the health care system according to their means. Even providing Medicaid fosters a kind of participation as the insured person is then better able to take responsibility for her health and to be a more productive member of the community. 12 For these reasons, it would seem that linking health insurance and health care to immigration status is simply a mistake.

Of course, immigrant populations are currently uninsured at high rates and will remain so despite the implementation of the Affordable Care Act. In this current milieu, how should our health systems respond to the immediate need in a hospitable manner?

#### Practicing Cultural and Medical Hospitality: Mission-Based Care for Immigrants

Our mission to care for the poor and the disenfranchised sometimes doesn't discriminate. However, we must not simply view underserved populations as a missionbased burden to be borne stoically. We must also consider the opportunities. Outreach to select patient populations can meet the maxim of "doing well while doing good." Immigrant populations are growing in the United States and, in many markets, represent the majority of market growth. These populations are critical to our local economies as well. In 2008, the Selig Center for Economic Growth at the University of Georgia indicated that the Latino population in Illinois represented \$41 billion in purchasing power. Hospitals and other health care organizations can garner new market share, newly insured patients and new revenues by reaching out to immigrant populations. That is the "doing well" part. They can also provide care in a culturally sensitive and mission driven way by thinking about the ways to better accommodate immigrant patients. And that is "doing good."

While the ACA's coverage expansions will not apply to undocumented immigrants, access for other immigrant patients will improve with the ACA, e.g., immigrants eligible for

subsidies in the exchanges, including those recently arrived who are excluded from Medicaid because of the five year bar. There will undoubtedly be additional conversations about caring for our immigrant patients. Thus hospitals and other health care facilities are compelled to think about the practical approaches they can take to provide mission-based care for these varied patients.

Many hospitals have already done substantial work around caring for the varied populations of patients who seek care from them. According to the website for New York-Presbyterian Hospital, "New York-Presbyterian offers an extensive language assistance program for its patients, including more than 58 onsite interpreters and other interpretation services available for up to 120 languages. In 2005, the Hospital provided more than 115,000 interpretations in 72 different languages all cost-free to the patient." That is impressive. For the majority of hospitals, the interpretation needs of patients are aggregated into a few languages. But, in addition to language assistance, hospitals and other health care organizations need to be sensitive to the cultural and religious beliefs of patients who seek services there as well. Administrators in faith-based institutions are called to care for the whole person--body, mind and spirit, and so, in Catholic health care, we are called to provide for the diverse needs of our immigrant patients. Outlined here are several practical steps hospitals and other health care facilities can take to ensure awareness of and responsiveness to immigrant patients' needs.

#### 1. Self and Institutional Education

a. What are the demographics of your patient population?

- b. What about the demographics of your service area?
- c. What are the subgroups within those demographics, i.e.,
  Mexican, South American,
  Cuban, etc.?
- d. What do administrators and staff need to know about these cultures?

#### 2. Response to What Is Learned

- a. Language: Consider what medical interpretation services are needed on site, via phone or through Skype-like technology. Also, consider using iPad or smart tablet apps that can translate non-clinical information such as directions to navigate through the facility. One example of such an app is iTranslate which can provide written or spoken translation from an iPad.
- b. Religious Beliefs: The fact that different religions have food and modesty beliefs needs to be taken into account. Ensure that a varied menu is available to accommodate vegetarian or other nutrition needs. Also, consider the possibility of enhancing hospital gown privacy with pants and head covering caps for patients whose religion or culture requires additional modesty.

- c. Cultural beliefs: It is critical to be aware of and responsive, to the degree possible, to cultural norms. Some cultures have strong superstitions about illness, some are sensitive to the gender of the patient and the caregiver, and some include the entire family in the care process. While it is not always possible to accommodate all norms, being aware of them can assist staff in being more sensitive when providing care to patients.
- d. Clinical needs: Data available from the Centers for Disease Control (CDC) provides a roadmap for needs of populations. For example, among Latino patients, women are 2.3 times more likely to have no or late prenatal care. Diabetes occurs 1.6 times more frequently among Latino patients, and Latina patients are 1.6 times more likely to have cervical cancer.

Knowing the population disease trends will assist in developing clinical programs that are responsive to your patient demographics.

#### 3. Some Additional Steps

- Recruit hospital staff who are reflective of the population of patients being served.
- b. Provide diversity training and practice to facility staff as well as to the medical staff.
- c. Consider hiring a diversity leader.
- d. Ensure that facilities are language friendly—signage, interpretation services (medically certified) and nonmedical interpretation options.
- e. Provide culturally sensitive hospital gowns.
- f. Provide a menu that respects religious and cultural choices.
- g. Have a chaplain staff that is reflective of various beliefs or that is well versed in the nuances of various religions.
- h. Develop strong community relationships with churches, cultural organizations, and Federally Qualified Health Centers who can support your patient population.
- i. Create clinical programs responsive to population needs
- j. Develop Patient Financial Services expertise on Medicaid eligibility, exchange enrollment, etc.
- k. Help ensure that immigrants receive good information about the ACA and possible benefits they might be able to receive, and help them to enroll where they are eligible.

Many of the steps that need to be taken are not difficult or terribly costly, though some will require longer term planning and additional expenditures. But sensitivity training for staff and education of medical staffs are free and can begin now.

With or without the Affordable Care Act, our Catholic health care calling creates an urgency to care for these new and growing populations. It may be that not all hospitals can afford interpreters, or new signs, but education, awareness and calling will find us leading the way to welcome our immigrant brothers and sisters with hospitality and a commitment to changing policies and structures that do not adequately serve their health needs.

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Table A. Eligibility of Access to New Coverage Vehicles of the Affordable Care Act

Immigration Status	Individual policy	Individual policy	Medicaid Coverage
	purchase on exchanges	purchase on exchange	
		with premium subsidy	
Authorized > 5 years	Yes	Yes	Yes
Authorized < 5 years	Yes	Yes	No
Undocumented	No	No	No
DREAMers with	No	No	No
DACA status			

### The Catholic Medical Association's White Paper, "The POLST Paradigm and Form: Facts and Analysis"

"From the Field" in this issue of HCEUSA is completely dedicated to POLST. The controversy over POLST continues. Most recently, Linacre Quarterly (May 2013) published an article, "The POLST Paradigm and Form: Facts and Analysis" (described by the authors as a "white paper") that levels serious charges against the POLST paradigm and POLST forms. The article has been widely disseminated and has served as the basis for active efforts to discredit POLST and to attempt to prevent its adoption in various parts of the country. While the article raises legitimate concerns, it is also flawed in a variety of ways. Fr. Tom Nairn, OFM, Ph.D., senior director for ethics at CHA, has conducted a very careful analysis of the article and its claims. That analysis is provided here in its entirety in the hopes that it might be of assistance to anyone having to address the content of the article.

In addition, we are publishing a Q & A on POLST that provides helpful information with regard to many of the concerns raised about POLST. With permission of the author, the Q & A has reformatted written testimony by Amy Vandenbroucke, JD, Executive Director, National POLST Paradigm Program, offered to the Senate Special Committee on Aging at a June 26, 2013 Hearing.

The White Paper may be accessed at http://cathmed.org/assets/files/LNQ59%20FINAL.pdf.

Fr. Tom Nairn, OFM, Ph.D. Senior Director, Ethics Catholic Health Association St. Louis <a href="mairn@chausa.org">tnairn@chausa.org</a>

#### An Analysis of Arguments

In the May 2013 issue of *The Linacre Quarterly* (Volume 80, 2), a working group of the Catholic Medical Association published a White Paper on the POLST paradigm and form. This White Paper has since been widely distributed, especially among Catholic bishops. This paper analyzes the arguments utilized in the White Paper.

#### I. UNDERSTANDING OF POLST

The authors of the White Paper speak about the "POLST paradigm and form." This phrase is used throughout the paper (see, for example, p. 105). Although the White Paper does not actually define the POLST paradigm, it explains that the paradigm has three aims:

- The first is advance care planning; the model requires a discussion on care options between POLST representatives and patients or their surrogates.
- The second is integrating patient preferences into physicians' orders by recording them onto POLST forms. Each state adopts its own version of the form, but all forms share certain identical characteristics.
- The third is ensuring that the document "travels" with patients and remains applicable across all care settings. (p. 108)

In addition, the authors articulate seven requirements that they explain all endorsed programs must meet:

- 1. State or regional health care facilities and workers must recognize properly completed forms as current or (in some states standing) medical orders;
- 2. Training programs for POLST implementation must be instituted;
- 3. Forms should be recommended for persons who might die in the next year, who suffer from "chronic progressive illness and/or frailty," or who are elderly "with strong, specific informed preferences" about their EOL options;
- 4. The signatures of patients or their surrogates on POLST forms are "strongly" recommended, but often not required, as "evidence that patients or their legal representatives agree with the orders on the form";
- 5. POLST forms should be the preferred advance planning document in diverse health care settings ("e.g. emergency medical services, long-term care, and hospice"); their completion should be left voluntary; shared decision-making and patient wishes should govern their completion;
- 6. A plan should be developed for POLST implementation and ongoing evaluation;
- 7. "A single strong entity" should be identified who is willing to "accept ownership for the program" and is capable of implementing it." (p. 106)

The White Paper's source for the description of the aims of POLST is the work of Charles P. Sabatino. His own articulation of these aims, which he describes as "key tasks" (2010) or "core tasks" (2011), is as follows:

POLST requires a health care professional to initiate a discussion with the patient (or the
patient's authorized surrogate) about key advanced illness treatment options in light of the

- patient's *current* condition. The objective is to discern the patient's goals of care and preferences and the available care options.
- The patient's preferences are incorporated into medical orders, which are recorded on a highly visible, standardized form that is kept at the front of the medical order or with the patient if the patient lives in the community.
- Providers must ensure that the POLST form actually travels with the patient whenever he or she moves from one setting to another, thereby promoting the continuity of care and decision making. (This description of the three tasks appears in Sabatino and Karp, 3-4. The White Paper cites Sabatino (2010), p. 229, which expands upon and further explains each of these tasks.)

In their analysis of the evolution of POLST programs, Sabatino and Karp do give a brief definition of POLST:

In simplest terms, POLST is a tool for translating patients' goals of care into medical orders for a certain subset of patients – those with advanced, progressive illness and/or frailty. It represents a significant paradigm change in advance care planning policy by standardizing *providers*' communications prescribing a plan of care in a highly visible, portable way, rather than focusing solely on standardizing *patients*' communications. (p. 3)

#### They add:

In the broad framework of advance care planning, a key concept to understand is that POLST is not an advance directive like a living will or a durable power of attorney. Rather, it is an advance care planning tool that reflects the patient's here- and-now goals for medical decisions that may confront him or her and converts those goals into specific medical orders. (p. 4)

#### II. ANALYSIS OF ARGUMENTS DEVELOPED IN THE PAPER

The following analysis treats the arguments developed in the White Paper. The authors often repeat the same or similar argument with slightly different nuances throughout the paper. This analysis groups the arguments under eighteen rubrics that attempt to illustrate what various arguments have in common. Under each rubric, one will find (a) the statement(s) from the White Paper, (b) the citation which the White Paper provides, (c) an analysis of the White Paper's use of its sources, and (d) additional comments.

#### 1. AUTONOMY

#### Statement(s):

"Medical paternalism has been replaced by a culture of autonomy that values patient wishes in medical decision-making sometimes to a fault." (p. 105)

"Advocates for patient autonomy argue that living will statutes were insufficient to ensure that patient care reflects patient preferences, especially in cases of advanced stage illness when critical decisions need to be made." (p.107)

References, sources: Sabatino and Karp, (pp. 2-3); Brugger.

#### Analysis of the White Paper's use of sources:

Implied in the White Paper (and more explicit in documents that it cites) is the understanding that behind the POLST paradigm is a "faulty and dangerous conception of autonomy," (Brugger, p.161) which construes patient autonomy as free from any constraint.

#### Additional comments:

The *Ethical and Religious Directives* acknowledge that "neither the health care professional nor the patient acts independently of the other; both participate in the healing process" (Introduction, Part Three). The first core task of POLST is such interaction between the patient (or surrogate) and the professional. If such advance care conversations are properly executed, they are consistent with the ERDs and can be a safeguard against exaggerated patient autonomy.

It is striking that – although the issue of autonomy is brought up early in the document – an apparently more pressing issue for the White Paper is the possibility that the patient will be manipulated by the health care professional into requesting less than appropriate care.

#### 2. LIFE AS A FOUNDATIONAL GOOD

#### Statement(s):

There "are foundational goods in human embodiment that must be respected in the free choices of patients and surrogates alike." (p. 113)

#### Analysis of the White Paper's use of sources:

Although there is no explicit citation, this statement arises from the Catholic moral tradition in general and, more specifically, from the Catholic tradition on the conserving of life. (Cronin)

#### Additional comments:

This is an important consideration. The POLST paradigm and form are simply tools that may be used well or poorly, that may be used for good or for ill. There is nothing inherent in the paradigm or form that is improper. Rather it is the way in which they are used that can become problematic or beneficial from the point of view of the Catholic moral tradition.

#### 3. USE OF FACILITATORS

#### Statement(s):

"The POLST paradigm proposes that non-physician health care personnel . . . initiate advance care planning discussions with patients or surrogates. These 'facilitators' . . . act as front-line implementers of the POLST paradigm. Completed forms are then referred to clinicians for signatures." (p. 111)

"Under the POLST paradigm, non-physician facilitators undertake [the] critical communications process: they approach patients, initiate POLST conversations, 'assist in making informed end-of-life decisions,' complete the POLST forms, and submit the forms to doctors for their signatures." In some nursing homes, 72% of POLST forms were completed by facilitators and not physicians. (p. 117)

"Facilitator trainees, as non-physicians, have little or no preexisting knowledge regarding indications for and relative benefits and burdens of life sustaining treatments." (p. 117)

**References**, sources: Sabatino and Karp, 24; Gunderson Lutheran, Respecting Choices; CANHR Policy Brief, 3.

#### Analysis of the White Paper's use of sources:

The POLST paradigm does not *propose* the use of facilitators. What Sabatino and Karp explain is that "even though POLST is most directly tied to the physician's role, every state's POLST recognizes that other health care providers – such as nurse practitioners, physician assistants, other nurses and social workers – generally provide much if not most counseling and assistance in filling out POLST forms." It then explains, "More often than not the physician role is to verify choices made and the process used with the patient and then sign off on the orders." (Sabatino and Karp, p. 24).

The trained facilitator model that the White Paper describes is a program developed by Gunderson Lutheran Health System in La Crosse, Wisconsin. It has influenced POLST training in other states. The Appendix to this analysis describes the staged facilitation model used by Gunderson. According to this model, the facilitators work closely with the physician. Meetings between the facilitator, patient, and agent are in-depth meetings, and – especially in the "Last Steps" stage – there may be several advance care planning sessions. A physician cannot practically undertake such an in-depth conversation, but the physician or nurse practitioner does need to review the process with the patient. This is in fact what happens at Catholic hospitals that have initiated POLST and advance care planning. The White Paper gives no evidence that facilitators in fact have little knowledge of the burdens and benefits of life sustaining treatments.

#### Additional comments:

The use of auxiliary personnel in medical care settings has become commonplace. Regarding advance care planning, physicians have reported lack of time, skill and comfort for these sorts of conversations (see Hammes and Briggs, p. 47). Thus in many circumstances, auxiliary professionals are more adequately prepared to discuss end-of-life issues with patients than are physicians. The White Paper suggests that such personnel, "as nonphysicians, have little or no preexisting knowledge regarding indications for and relative benefits and burdens of life sustaining treatments" (p. 117). This statement is not adequate to the competence and training of these professionals. Furthermore, it does not adequately describe the actual collaborative relationship that exists and the importance of such professions in the end-of-life decisions. (See Adams et al.) Nevertheless, to the

extent that discussions with patients are not reviewed by a physician (in most states) or by a nurse-practitioner (in some states), this is an abuse of POLST.

The CANHR Policy Brief statement that 72% of POLST forms were completed by nonphysicians needs comment. The policy brief indicates that physicians did sign the forms but added that "physician participation in POLST completion appears to be tepid" (p. 3). The fact that a facilitator does the major work in participating in the dialogue with the patient or surrogate is not in itself a problem. Physicians, however, must be involved in the process. Simply to sign an already completed form without review is an abuse of POLST. This does not invalidate POLST but points to the need for education and training and for proper monitoring and evaluation. (Sabatino and Karp, pp. 19-20)

#### 4. PHYSICIAN-PATIENT RELATIONSHIP

#### Statement(s):

There is a problem of the potential weakening of the doctor-patient relationship: "Deprived of the security of a personal relationship with the physician, the patient may seek comfort through instruments like POLST." (p. 116)

#### Analysis of the White Paper's use of sources:

The White Paper gives no evidence that patients seek the comfort of POLST forms as an alternative to the security of a relationship with a physician. There is an issue here, but Sabatino and Karp describe it a *misperception* of POLST. They explain that POLST is a process and not merely a form. (p. 18) They give the example of New York that has defined an eight-step protocol, of which completing and signing the form is only one of the eight steps.

#### Additional comments:

Although at the beginning of the White Paper the authors acknowledge that an aim of POLST is to increase advance care planning, (p. 108) the paper never really discusses the larger POLST paradigm and its context of advance care planning but seems to limit POLST to the form that is completed. This is at best a very truncated understanding of POLST.

To the extent that the authors' criticism of POLST may be true in some circumstances, it seems that the remedy is to stress the importance of education about the goals and process of POLST. It is not simply a form to be filled out without appropriate training. If POLST is appropriately seen as a process within a larger context of advance care planning and not simply a form, the physician-patient relationship can actually be strengthened.

#### 5. NECESSITY OF TERMINAL ILLNESS

#### Statement(s):

"Although POLST is said to be designed for use by terminally and chronically ill elderly, there is nothing in most POLST programs or state POLST laws that actually limit it to this population." (p. 113)

"The POLST model legislation *annuls the requirement that a patient must be terminally ill* before he or she may direct the withholding or withdrawal of life-sustaining treatments." (p. 113)

"POLST was originally conceived for patients clearly at the end of their lives, in controlled settings, for whom disabling life-threatening complications were anticipated. Such restrictive parameters for use of POLST can be replaced with looser limits or almost no limits, as borne out in various locations throughout the country." (120; examples are given on p. 121.)

*References, sources:* Brugger, pp. 158-161; CANHR Policy Brief; Briggs, "Shifting the focus of Advance Care Planning," Innovations in End-of-Life Care, 2003; Delaware MOLST Coalition.

#### Analysis of the White Paper's use of sources:

Brugger's article cites Colorado law on living wills "going back two decades" that limits proper compliance to use for a person in a terminal condition (p. 158). However, the U.S. Supreme Court has ruled in Cruzan v. the Missouri Department of Health (1990) that a person has a liberty interest under the Due Process Clause of the 14<sup>th</sup> Amendment in refusing unwanted medical treatment. It does not limit this liberty interest to persons with terminal illness.

#### Additional comments:

Beyond the legal perspective, the Catholic moral tradition regarding benefits and burdens is more nuanced than the White Paper indicates, and is not limited to terminal illness (See Cronin). Terminal illness as a moral pre-condition for assessing extraordinary means would preclude such traditional factors of moral teaching on end-of-life care as *vehemens horror*. The presence of chronic critical illness, advanced progressive disease, or frailty means that a person who technically may not be at an end-stage of a terminal condition may nevertheless face the prospect of a life-ending event.

The paper might also exhibit some confusion of POLST with the larger process of advance care planning (of which POLST is the final stage). Advance care planning is recommended for all adults, while POLST should be limited to those in the last stages of a chronic illness or the frail elderly (see the Appendix). However, to the extent that an expansion of POLST as described in the White Paper could occur, it would be an abuse and would contradict the articulated philosophy of POLST.

### 6. MOVEMENT FROM END-OF-LIFE PLANNING TO THE COMPLETION OF POLST FORMS

#### Statement(s):

"The goal of an end-of-life planning meeting can easily change from a thorough discussion of values, wishes, and options to merely completing the form." (p. 116)

#### Analysis of the White Paper's use of sources:

No evidence is given that this is the case. The White Paper indicates that POLST is a "paradigm" and not simply a form. Furthermore, it acknowledges (108) that one of the three aims of POLST is its inclusion in a larger advance care planning conversation. Advance care planning involves a

"process of understanding, reflection, and discussion. . . . This ideology is inherently and importantly different from merely the completion of advance directive documents." (Hammes and Briggs, p. 90)

#### Additional comments:

The statement seems to reveal an incomplete understanding of POLST and advance care planning in general. As discussed earlier, descriptions of POLST place it in the context of advance care planning. Catholic health care institutions that have initiated advance care planning acknowledge not only the necessity but also the benefits of such a thorough discussion of values and beliefs in relation to clinical options.

#### 7. USE OF CHECK BOX LIST

#### Statement(s):

"The POLST form offers a simple check box list of treatment options. Complex medical decisions are reduced to over simplified scenarios that do not reflect the nuances of actual medical practice." The patient must pre-determine either to consent or reject. "Patients may make their choices weeks, months, or even years before choices will be carried out." They do so not knowing "the exact nature of their [future] conditions or the range of reasonable treatment options." Proper patient care cannot be reduced to a simple predetermined check list. (p. 114)

#### Analysis of the White Paper's use of sources:

There are problems with the check box approach, and the authors are correct in stating that "proper patient care cannot be reduced to a simple predetermined check list." However, the check list is possibly less problematic in the POLST form than in a living will. The philosophy behind POLST involves a "shift of emphasis from the completion of legal forms to an ongoing process of advance care planning. Advance care planning involves an iterative process of communication over time among the individual, the health care provider, the proxy, and others who may participate in the health care decision-making process to discern the individual's priorities, values, and goals of care. Documentation remains important but as a tool *secondary to and supportive of* the communication process." (Sabatino and Karp, p.2, my emphasis) Therefore, if the philosophy of POLST is respected, and the form is considered as part of advance care planning, the choices expressed result from dialogue between the patient and professional(s), reflect the patient's current physical condition, and therefore more accurately reflect current treatment options than the check box of a living will.

#### Additional comments:

There are two aspects to the check box list of treatment options, (1) that of the person(s) executing the POLST and (2) that of the physicians and especially nonphysician emergency medical personnel who must interpret the form. As discussed in the analysis, checking the box in the first instance is supposed to be the result of a conversation between the professional and the patient or surrogate. It represents the appropriate option given current advance care planning related to the patient's actual

medical condition. Typical procedures and policies for the implementation of POLST in health care facilities compare the patient's actual condition with the POLST order.

The second aspect involves especially emergency medical personnel. The check box design offers relatively clear guidance, although Sabatino and Karp indicate that EMS personnel believe that POLST still "offers too many choices, making it challenging to act on the scene" (p.18). The authors add that "the experience in successful POLST states has been that training modifies this perception" (p. 18). Others have observed that the check box format offers a helpful standardization, especially with the advent of electronic medical records.

#### 8. PATIENT SIGNATURE

#### Statement(s):

POLST forms "may not require the patient's signature." (p. 114)

#### Analysis of the White Paper's use of sources:

Most states in fact do require the patient's signature. Those that do not require the signature recommend it. New York recommends but does not require the patient's (or surrogate's) signature; it also recommends but does not require the signature of two witnesses. (Sabatino and Karp, p. 11)

#### Additional comments:

The White Paper acknowledges the normal response to this objection that traditional medical orders operate with only a clinician's signature, (p. 114) a response that the White Paper considers unsatisfactory.

Requiring the patient's signature in all states would likely strengthen POLST by serving as a safeguard ensuring that orders were not signed without the patient's or surrogate's knowledge and informed consent.

#### 9. NON-TREATMENT BIAS

#### Statement(s):

"We have concerns with the verbiage used and the underlying psychology of the POLST form, which seem to carry a bias in favor of non-treatment." (p. 115)

"Facilitator training scripts have been found to have inordinate emphasis on burdens of life sustaining treatments while dismissing the disadvantages and potential complications of rejection of treatments." (p. 117)

*References, sources: Respecting Choices.* Also cited: Washington State POLST (The White Paper objects to the term "prolonged," which it maintains has negative connotations.) Wisconsin POLST (This POLST form substitutes the nomenclature "aggressive treatment" for "full treatment.")

#### Analysis of the White Paper's use of sources:

It is not clear that the term "prolong" in fact biases the discussion. For example, the *Declaration on Euthanasia* favorably uses the term "prolongation." Similarly, in 1981 the then Pope John XXIII Center (now NCBC) published the book entitled, *Moral Responsibility in Prolonging Life Decisions*.

The terms "aggressive therapies" or "aggressive interventions" also have a history in contemporary medicine and are not necessarily pejorative terms. The term "aggressive medical treatments" is used in *Evangelium Vitae*, par 65, and the *Catechism of the Catholic Church* actually speaks of "overzealous" treatment (par 2278).

Regarding the general question of bias in favor of non-treatment, no state requires that every section of the POLST form be completed. In most states there is an explicit presumption that sections left blank should be interpreted as the patient's wanting full treatment in that area.

The White Paper also refers to the scripts that are part of the *Respecting Choices* program. The scripts and fact sheets do seem to emphasize the burdens of treatment for those in end-stage illness and the frail elderly.

#### Additional comments:

To the extent that such negative bias occurs, there is a problem. However, the White Paper does not establish that there is a bias in favor of non-treatment. In the population for whom the POLST is intended, there may likely be a valid decision against full treatment in favor of a more appropriate limited treatment. Such treatment would not be based on bias but on objective data. This would be in accord with Catholic moral principles. Hickman et al., for example, describe that, while there are a large number of nursing home patients who opted for only comfort care, the largest category indicated preference for limited care, which would seem appropriate considering this population. (p. 1246). Again, there is good reason why the smallest group would indicate full treatment (though this option in fact was also chosen).

Although some of the *Respecting Choices* scripts may appear to be biased in favor of non-treatment, the statements are also accurate descriptions of burdens. This emphasis on burdens is understandable given both the population in question and over-optimistic general perceptions of success that many patients have. For example the statement in the scripts regarding the relatively low success rate of CPR is important in light of the patients' perceived success rate, often based on watching medical dramas. In Catholic facilities, however, facilitators need to be familiar with the *Ethical and Religious Directives* and to ensure that their communication with patients is in accord with Catholic moral teaching.

### 10. SUSPICION REGARDING "UNWANTED TREATMENT" Statement(s):

The White Paper quotes Hickman: "POLST program's association with less use of unwanted lifesustaining treatments in a large, geographically disparate sample is unprecedented." It challenges this

assertion, asking that in light of "innovations of the POLST paradigm – facilitated informed consent, unwitnessed interviews, lack of patient signature – how can medical professionals be confident that treatments are truly unwanted?" (p. 120)

References, sources: Hickman et al., p. 1246.

#### Analysis of the White Paper's use of sources:

What the study describes as innovations of the POLST paradigm are not necessarily part of the paradigm at all. Two of the three states studied by Hickman, et al. mandate patient signatures. Since the discussion deals with nursing homes, the "unwitnessed interviews" seems to refer to the CANHR Brief's discussion that, contrary to California's law requiring nursing homes to require that an ombudsman sign an advance directive form as witness, this is not the case with POLST (pp. 4-5). Facilitated informed consent has already been discussed under #2.

#### Additional comments:

There seems to be a suspicion throughout the White Paper that patients are led to make treatment choices contrary to their best interests. Yet little evidence is given for this. Terms like "can," "may," or "might" are used when such statements are made. The conclusion of the Hickman study states: "Study findings suggest use of the POLST program offers significant advantages over traditional methods to communicate treatment preferences in the nursing facility setting." (p. 1247)

### 11. MEDICALLY ASSISTED NUTRITION AND HYDRATION Statement(s):

"Every POLST form has a section dedicated to the refusal of nutrition and hydration. But Pope John Paul II clarified that the administration of nutrition and hydration, even by artificial means, 'should be considered *ordinary* and *proportionate*, and as such morally obligatory, insofar as and until it is seen to have attained its proper finality.' In all but cases when a patient is imminently dying or rare instances where food and water are no longer adequate to sustain bodily life or their administration causes excessive suffering, the decision to forego them would be wrongful." (p. 113)

"The POLST gives the impression that patients who are fed and hydrated via technical means are being kept alive unnaturally." (p. 115)

References, sources: Pope John Paul II, "On the 'Vegetative State."

#### Analysis of the White Paper's use of sources:

The 2004 Allocution was delivered at a conference on the persistent vegetative state, not end-of-life care. Pope John Paul II explains that medically administered nutrition and hydration is "in principle, *ordinary* and *proportionate*, and as such morally obligatory, insofar as and until it is seen to have attained its proper finality, which in the present case consists in providing nourishment to the patient and alleviation of his suffering." The distinctions articulated in Directive #58 of the *Ethical* 

and Religious Directives are important in this context. In end-of-life care, medically assisted nutrition and hydration can be considered extraordinary means.

#### Additional comments:

The administration of medically assisted nutrition and hydration at end of life is more complicated – and exceptions regarding the use of medically assisted nutrition and hydration more common – than the White Paper indicates. Pope John Paul himself acknowledged that in individual cases medically assisted nutrition and hydration can be ineffective or excessively burdensome.

Regarding the statement on p. 115, the White Paper is correct in suggesting that "medically assisted" is a description that is less likely to be misinterpreted than "artificial." It should be noted, however, that the language of "artificial" is not necessarily pejorative. In his 2004 Allocution, Pope John Paul did speak of water and food being provided "by artificial means" and continued "administration of water and food, even when provided by artificial means, always represents a *natural means* of preserving life, not a *medical act*."

#### 12. MANDATORY COMPLETION OF FORMS

#### Statement(s):

"Proponents often imply that once a program is implemented, POLST forms are required, recognized and binding." Furthermore, according to the proposed regulations around the Maryland MOLST, certain facilities "will be required to accept, update, and complete a MOLST form for each patient during the admission process." (p. 122)

*References, sources:* Maryland MOLST form; Oregon POLST; Maryland Department of Health and Mental Hygiene Regulations 10.01.21.04.

#### Analysis of the White Paper's use of sources:

No state mandates that patients complete POLST forms (Fagerlin and Schneider, p. 11). Some states mandate that the forms/process must be *offered*, though patients are not required to have POLST/MOLST.

Maryland's MOLST form went into effect January 1, 2013. It does state that in certain facilities a MOLST form must be completed. According to Regulation 10.01.21.04, however, "completing" means: "(1) certifying, when applicable, the bases for the orders contained therein; (2)completing section one [on use of CPR] for all patients and only those sections two through nine of the form that are related to the patient's current medical condition and wishes for care; and (3) signing and dating the MOLST form." The form indicates in bold print that preparation of the MOLST form is voluntary. It also clearly states that if a patient or surrogate does not make any selection regarding CPR status, then CPR must be attempted.

It is correct that there is no place on the Maryland MOLST form for the signature of the patient, and, as suggested above, this is a problem. However, the physician or nurse practitioner must certify

that the form is a result of a discussion with and informed consent of the patient or surrogate. Furthermore, the form must be given to the patient or surrogate within 48 hours or earlier if the patient is discharged.

#### Additional comments:

If those offering POLST communicate that it is mandatory, this is an abuse of POLST. An implication of the White Paper is that the Maryland MOLST procedure is not voluntary and could be (legally) enacted without the patient's knowledge and/or consent. Although such an inference might be made by reading only the summary of the legislation, in viewing both the form and the actual regulations this is not the case.

In many states, POLST must be *offered* to all nursing home residents, but it is not mandatory for the patient to have a POLST form. Sabatino and Karp emphasize the importance of education and training, including monitoring and evaluation to counteract possible abuses. (pp. 19-20) It seems that proper education, monitoring and evaluation would rectify these abuses.

### 13. MANDATORY COMPLIANCE WITH POLST ORDERS Statement(s):

Ten states have printed on top of POLST form: "First Follow These Orders, Then Contact Physician." Licensed health care professionals are placing their professional conduct at risk by carrying out orders that may not be appropriate for the patient. (p. 117)

In Maryland, "the law says that a facility must comply with all medical orders in a MOLST form regardless of whether the physician or nurse practitioner who signed the form has admitting privileges or is otherwise credentialed at the facility." (p. 122)

"The administrative rules in Oregon state that physicians and physician assistants must comply with POLST, even if the physician, physician assistant, or nurse practitioner who executed the form does not have admitting privileges at the facility where the patient is being treated." (p. 122)

*References, sources:* The states mentioned are: Wisconsin, West Virginia, Tennessee, Washington, Pennsylvania, Minnesota, Louisiana, Hawaii, California, Colorado. See also Maryland's Department of Health and Mental Hygiene Regulations 10.01.21.04.

#### Analysis of the White Paper's use of sources:

According to Sabatino and Karp, a key barrier to implementation of patient's preferences is the implementation of an actionable plan that reflects those wishes. "These disconnects typically occur when the individual is in an advanced stage of illness when critical care decisions have to be made in crisis mode. Advance directives have not been effective in these situations for several reasons, including their frequent lack of availability when needed, their lack of clinical specificity with respect to here and now medical decisions, and their lack of integration into medical orders." (pp. 2-3) The

POLST form, as a medical order, is designed to be specific regarding what emergency services personnel should or should not initiate.

Sabatini and Karp also explain that in most states there is a pragmatic balancing of continuity of care goals with the hospital's quality of care goals: "The result generally is an expectation that POLST will be reviewed upon admission and either reaffirmed, revised, or revoked as appropriate. But if there is no time to review the orders due to the patient's condition, incapacity, or lack of available authorized surrogate, then orders can be followed, even if not signed by physician with admitting privileges." (pp. 17-18)

#### Additional comments:

The White Paper addresses the issue of compliance in the context of "respect for conscience." Sabatini and Karp explain that the question regarding admitting privileges deals with the portability of the form.

Many state laws offer immunity for providers; others indirectly give immunity by acknowledging the legality of the POLST document and therefore the need of medical personnel to follow it. According to Sabatino and Karp, "All the survey states except Minnesota provide immunity from civil or criminal liability and from disciplinary actions for complying with POLST orders and procedures." (p. 11) With respect to the circumstances of ascertaining a patient's wishes when there is no time to review the orders, following such orders is the most reasonable option for determining the patient's wishes and as such is an ethically-appropriate action to take.

### 14. POLST OVERRIDES ADVANCE DIRECTIVES Statement(s):

"In some jurisdictions, POLST forms override all other advance directives, including the agent specified under a durable power of attorney." (p. 120)

References, sources: Rev. John Tuohey, 2011 CHA webinar.

#### Analysis of the White Paper's use of sources:

According to Fagerlin and Schneider, their survey informants did not flag inconsistencies between POLST forms and advance directives as an issue. According to their study, POLST forms control decisions in three states; the most recent form in two states. (p.12) The CANHR Policy Brief, however, raises the issue that according to the wording of the legislation in California, a third party, such as the agent in a DPA, can execute a POLST form that is different from the wishes of the patient as expressed in the advance directive. (p. 4)

#### Additional comments:

Although the specific problem that the White Paper raises does not seem to be an actual problem, there is the possibility that a third party can overrule what the patient has specified. The CANHR

Policy Brief suggests a remedy for this by specifying that "the most recent treatment preferences expressed by the patient should prevail." (p. 7)

#### 15. USE OF POLST IN NURSING HOMES

#### Statement(s):

"Nursing home residents with POLST forms are far more likely to have orders limiting life-sustaining treatments beyond 'No CPR' than those with conventional advance directives (98.1% v. 16.1%)." (p. 120)

References, sources: Hickman, et al, p. 1244.

#### Analysis of the White Paper's use of sources:

The actual quote is: "When CPR orders were excluded from the analysis, residents with POLST forms had significantly more standing orders reflecting life-sustaining treatment preferences than non-POLST users (98.0% vs 16.1% *P*<.001)." (p. 1244)

#### Additional comments:

The Hickman study speaks of respecting patient preferences regarding life-sustaining orders, not the issuing of orders that limit life-sustaining treatments.

### 16. COST SAVINGS/CONFLICT OF INTEREST Statement(s):

"It seems reasonable to consider whether hospital-employed facilitators create a financial conflict of interest in their institution-appointed duties. Given that hospital Medicare reimbursement is a fixed price based on admission diagnosis, when patients agree to fewer life-sustaining treatments based upon conversations with negatively-biased facilitators, hospital costs decrease while profits increase. This is not to imply that administrators seriously ponder financial trade-offs for their clients, Nevertheless, significant cost savings have been achieved at the end of life with POLST/facilitator programs and may constitute a powerful driver for subscription in facilitator programs." (p. 118)

*References, sources:* Reinhardt, 2009; Gunderson Lutheran Health System, "Transforming Healthcare: Advance Care Planning."

#### Analysis of the White Paper's use of sources:

The actual situation of hospital reimbursement is more complicated than the White Paper indicates. Uwe Reinhardt's short blog entry itself is more nuanced than the White Paper suggests. Furthermore, the statement "when patients agree to fewer life-sustaining treatments based upon conversations with negatively-biased facilitators, hospital costs decrease while profits increase" contains several unexamined assumptions and is made without giving evidence.

Cost savings should be an appropriate goal for medical facilities. It demonstrates responsible stewardship of resources. The White Paper implies that *profits* drive the utilization of POLST. No

evidence is given. An important element of advance care planning programs such as *Respecting Choices* is improving quality outcomes. (See Hammes and Briggs, p.149-163)

#### Additional comments:

The White Paper's inference regarding conflict of interest is given as conjecture without evidence. The Catholic moral tradition acknowledges the cost of non-beneficial medical interventions as problematic. If advance care planning can both decrease costs and improve quality, it should be commended. Finally, the implication that cost savings would be realized as increased profits for a hospital does not follow from the facts, since part of the potential savings come from the fact that a patient would choose not to return to the hospital for end-of-life care.

Furthermore, the choice of limited care, palliative care, or hospice does not necessarily mean a quicker death. Studies have shown that appropriate palliative care increases survival rates in certain populations. The use of quality, appropriate care that does not needlessly expend health care resources is a moral driver here.

### 17. INSTABILITY OF PATIENT CHOICES Statement(s):

"There is evidence that the stability of recorded [patient] decisions is low. Researchers have found that patient preferences change up to 77% of the time when questions are asked differently." Furthermore, "patients are frequently uncertain when their wishes are initially recorded (up to 45% of the time)." Answers to advance decision making documents are shaped by the way questions are asked. (p. 119)

References, sources: Fagerlin and Schneider, p. 33; Sudore and Fried.

#### Analysis of the White Paper's use of sources:

The actual quote from Fagerlin and Schneider (p. 33) is: "In one study, '201 elderly subjects opted for the intervention 12% of the time when it was presented negatively, 18% of the time when it was phrased as in an advance directive already in use, and 30% of the time when it was phrased positively. Seventy-seven per cent of the subjects changed their minds at least once when given the same case scenario but a different description of the intervention." Fagerlin and Schneider do not want to eliminate all advance directives but to limit them to patients "whose medical situation is plain, crisis is imminent, preferences are specific, strong, and delineable, and who have special reasons to prescribe their care." (p. 30)

Similarly, Sudore et al. advocate a shift from "premature treatment decisions based on incomplete or hypothetical information" to health care decisions "based on a more comprehensive set of considerations, including the current clinical context, shifting and evolving goals, and patients' and surrogates' needs" p. 257). In fact, this is what POLST is attempting to do, and this is consistent with Catholic teaching on ethically proportionate and disproportionate means of sustaining life.

#### Additional comments:

The argument of Fagerlin and Schneider seems to favor POLST rather than argue against it. The conditions they describe are precisely those that serve as the basis for the philosophy of POLST. The quote from Fagerlin and Schneider seems to relate to the fact that answers are shaped by the way the question is asked rather than by the stability over time of the answers themselves. This demonstrates the importance of the role of advance care planning as opposed to simply filling out a form, be it a living will, durable power of attorney, or POLST.

Given the nature of POLST and its advance care planning context, there seems to be less chance of instability of patient decisions over time than with advance directives.

### 18. CATHOLIC TEACHING ON ADVANCE DIRECTIVES Statement(s):

Regarding advance directives in general, Directive #24 of the *Ethical and Religious Directives* "should not be read as an endorsement by the U.S. bishops of advance directives or advance decision making." (p. 123)

References, sources: Ethical and Religious Directives for Catholic Health Care Services.

#### Analysis of the White Paper's use of sources:

The White Paper is technically correct. The concern expressed by the U.S. bishops has been to ensure that people execute advance directives according to Catholic teaching rather than to endorse advance directives themselves. This can be seen in the references to advance directives in the *Ethical and Religious Directives*. Having said this, it should also be noted that the bishops have in fact recommended that Catholics make use of advance directives. For example, in its *Pastoral Message on Growing Older Within the Faith Community*, the USCCB stated: "You may worry about being unable to communicate your desires regarding such serious matters as life support systems. Advance directives can help your loved ones know your wishes."

#### Additional comments:

Directive 24 acknowledges that advance directives are morally acceptable in Catholic health care facilities provided that they do not contradict Catholic moral teaching. It needs to be emphasized, however, that POLST is not an advance directive. As Sabatino and Karp explain, "it is an advance care planning tool that reflects the patient's here-and-now goals of medical decisions that may confront him or her today and converts those goals into specific medical orders." (p. 4) It is dealing with the parameters of current, not future, care, and is supposed to be revised as care planning changes. Several POLST forms (though not all) indicate dates for review – often when the patient is transferred from one care setting to another.

#### **III. CONCLUDING COMMENTS**

The many arguments put forth in the White Paper do not invalidate POLST. For this reason, this analysis does not evaluate the recommendations of the White Paper. (pp. 124-127)

Having said this, the current implementation of POLST is not without problems. Several of the arguments in the White Paper point to these problematic elements of the POLST paradigm but do not thereby invalidate the paradigm itself. It can be improved, however. Wenger et al. have shown that difficulties remain in interpreting POLST to make treatment decisions, in avoiding family disagreements regarding POLST directives, and in physician participation. (p. 54)

In order for a more beneficial implementation of POLST to occur, it seems that the following elements are needed:

- The target audience of POLST needs to be clear those with advanced, progressive illness and/or frailty.
- The misunderstanding that POLST is another advance directive needs to be corrected.
- The quality of the advance care planning sessions that give rise to the POLST document is crucial. They should be seen as true dialogues between the health care professional and patient and/or surrogate. It may help if other family members were also present.
- Appropriate education and training are needed on all levels.
- Appropriate monitoring and evaluation need to be developed.
- A neuralgic element among many critics of POLST can be overcome by requiring the signature of patients or surrogates on POLST forms.

This analysis has been provided in the hope of continuing the discussion of the appropriateness of POLST and the process of advance care planning.

### APPENDIX: "RESPECTING CHOICES" STAGED APPROACH TO ADVANCE CARE PLANNING (ACP)

The facilitators that the White Paper mentions are part of Gunderson Health System's *Respecting Choices* Program, which has expanded to several health care systems, including Catholic systems. The model incorporates three stages, each of which has specific training of facilitators. Thus, the training of professionals as facilitators is specific to the population that they will be serving in the appropriate stage of ACP. In the last stage, in which POLST forms are executed, nurses or social workers are employed. *Respecting Choices* describes the three stages in the following way:

• **First Steps** is appropriate for all adults, but ideally is initiated as a routine of care for those over 55. The goals of this stage of planning are to motivate individuals to participate; select

a qualified health care agent(s) appointed in a power of attorney for health care document; and provide instructions for goals of care in the event of a permanent, severe neurologic injury.

- Next Steps is initiated by health care providers caring for patients with chronic, progressive illness who are experiencing a decline in function, complications, or more frequent hospitalizations. The goal of this stage of ACP is to engage patients in understanding their illness progression and related treatment options, including benefits and burdens of lifesustaining treatment, and to prepare health care agent(s) to make decisions about goals of care in selected "bad outcome" scenarios.
- Last Steps is initiated as a component of quality end-of-life care for frail elders and those whose death in the next 12 months would not be a surprise. The goals of this stage of planning are to assist individuals or their designated health care agents to make timely, proactive, and specific end-of-life decisions (e.g., cardiopulmonary resuscitation, airway management, artificial nutrition, hospitalization) and convert these decisions into medical orders that can be followed throughout the health care continuum.

Thus, POLST is part, but only a part, of a regular, ongoing process of Advance Care Planning. Facilitators work closely with physicians and other care providers. (Hammes and Briggs, pp. 26-27, pp. 92-97)

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Editor's Note: The following Q & A regarding POLST is reformatted from the written testimony ("Renewing the Conversation: Respecting Patients Wishes and Advance Care Planning") by Amy Vandenbroucke, JD, Executive Director, National POLST Paradigm Program, offered to the Senate Special Committee on Aging at a June 26, 2013 Hearing.

#### What is POLST?

The Physician Orders for Life-Sustaining Treatment (POLST)<sup>1</sup> is a tool for translating patient's goals of care into medical orders so that they are easily located and portable across care settings. POLST is not just a specific set of medical orders documented on a form; it is also an approach to end-of-life planning based on conversations between patients, loved ones, and medical professionals. The POLST Paradigm is designed to ensure that seriously ill patients can choose the treatments they want and that their wishes are honored by medical providers.

A key component of the system is thoughtful, facilitated advance care planning conversations between health care professionals and patients and those close to them. Completion of a POLST form requires shared decision making between the health care professional signing the form and the patient, or his/her legally authorized health care representative identified pursuant to state law. In order to complete the POLST form, there must be a discussion of the patient's diagnosis and prognosis; the available treatment options given the current circumstances, including the benefits and burdens of those treatments; and the patient's goals of care and preferences of treatment. Together they reach an informed decision about desired treatment, based on the person's values, beliefs and goals for care. Then, if they wish, their health care professional completes and signs a POLST form based on the patient's expressed treatment references.

### Who is POLST for?

POLST is <u>not</u> for everyone; only patients with serious advanced illnesses should have a POLST form. For patients where a POLST is appropriate, their current health status indicates the need for standing medical orders for emergent or future medical care. For healthy patients, an advance directive is an appropriate tool for making future end-of-life care wishes known to loved ones. The general guidance is that the POLST form is for seriously ill patients for whom their physicians would not be surprised if they died in the next year. It would be inappropriate to provide a POLST to all patients.

### Two key tenets of POLST are:

(1) POLST is voluntary because everyone has the right to make his or her own health care decisions; the National POLST Paradigm Task Force (NPPTF) does not endorse programs where completion of a POLST form is mandatory.

(2) POLST must be easily modified or revoked. Oregon's POLST Registry shows about 15% of POLST forms submitted to the registry each month are modifications of a previous POLST form. As the disease progression continues, patient desires for certain treatments may change, so it is fundamental to the POLST Paradigm Program that POLST forms be easily modified.

### What does the POLST form contain?

The POLST form varies among states but states endorsed by the National POLST Paradigm Task Force have all met the same standards.

POLST forms are divided into a couple of key sections; the order may vary by state. For illustration, the Oregon POLST Form is used as an example.

<u>Section A:</u> Cardiopulmonary Resuscitation (CPR). These orders apply only when the patient has no pulse <u>and</u> is not breathing; this section does not apply to any other medical circumstance. If the patient wants CPR, the box should be checked and full CPR measures should be carried out and 9-1-1 called. If the patient does not want CPR, the box should be checked and CPR should not be performed.

<u>Section B</u>: <u>Medical Interventions</u>. This section is designed to guide care in an acute situation when the patient is not in cardiopulmonary arrest. There are three levels of medical interventions generally found on POLST forms:

- i. Comfort Measures Only/Allow Natural Death. The treatment plan is to maximize comfort through symptom management. Antibiotics may be used as a comfort measure. This should be ordered if a patient's goal is to maximize comfort and avoid hospitalizations unless necessary to ensure comfort needs are met.
- ii. **Limited Additional Interventions**. The treatment plan is to hospitalize if needed but to void mechanical ventilation and generally avoid ICU care. This should be ordered if a patient's goal is to obtain treatments for reversible conditions or exacerbations of his/her underlying disease with the goal of restoring the patient to his/her current state of health. Examples include hospitalization for dehydration or for pneumonia.
- iii. **Full Treatment**. The treatment plan should include all life-sustaining treatments possible, including intubation, advanced airway intervention, mechanical ventilation, cardiodiversion, transfer to hospital and use of intensive care as indicated with no limitation of treatment.

While it is possible to order Do-Not-Resuscitate (DNR) in Section A, but Full Treatment in Section B, in this circumstance, a patient would want all measures provided but would not want to be resuscitated if those attempts fail and their heart stops. It is not possible to order CPR in Section A

and Comfort Measures Only in Section B because, in providing CPR, the next step is for intubation and ventilation, which is not consistent with the Comfort Measures Only option.

<u>Section C</u>: Artificially Administered Nutrition. These orders indicate the patient's instructions regarding the use of artificially administered nutrition for a patient who cannot take fluids by mouth. Statutes vary among the states as to the standard for evidence required to limit tube feedings. For endorsement, the NPPTF requires POLST forms to clearly state that "food and fluids must be offered as tolerated."<sup>2</sup>

It is also a requirement that comfort measures <u>always</u> be provided to patients and that information be clear on the POLST form.

#### How does the POLST form work?

Since POLSTs are medical orders, they can be made to be easily located in an emergency since they are part of the patient's medical record. There is no requirement for electronic medical record (EMR) systems to provide such easy access to a POLST, or an advance directive, but it should be so that health care professionals are confident they can locate patient wishes in an instant during an emergency. Additionally, the original POLST form is given to the patient to keep (copies are put in medical records). States use brightly colored forms for easy identification by emergency personnel.

Several states, including Oregon, West Virginia, Idaho, Utah and New York, have registries for POLST forms, ensuring emergency personnel and health care professionals know the treatment wishes of their patients during an emergency. This provides a third avenue in which a form can be located in an instant, because health care professionals can call the 24/7 registry line and get information about a patient's POLST form.

So, for example, in an emergency in Oregon, when EMTs are called to a scene they will arrive and are trained to look at/in the refrigerator for a bright pink form. Patients and families are told that this is where the form should be kept. Additionally, EMTs are trained to call the Oregon POLST Registry anytime: (1) they suspect a patient has a POLST; (2) they are told a patient has a POLST but are unable to locate it; (3) the patient has a chronic, progressive illness; (4) the patient is a frail or elderly patient; and (5) if a POLST form is produced on the scene but there is a problem or question as to the orders selected, or validity of the form.

The value in having a single form for medical orders allows emergency services personnel to: (1) follow medical orders in the field because they are trained to find information in an instant and (2) incorporate such a procedure in their scope of practice.

### May a POLST be revised or voided?

As a patient's disease progresses his/her goals of care may change and so it is important that the POLST be easily amended or voided; both are easy procedures in endorsed states.

### Revising a POLST Form.

The health care professional responsible for the patient's care should review and update the POLST form, with the patient or his/her surrogate, as needed based on the patient's medical condition and treatment preferences. At a minimum, the POLST should be reviewed in the following circumstances:

- (a) When the patient is transferred from one care setting or care level to another;
- (b) When there is a substantial change in the patient's health status; and
- (c) When the patient's primary care professional changes.

A patient with capacity, or his/her valid surrogate when the patient lacks capacity, may also initiate a revision of a POLST form at any time.

Revisions of POLST forms generally require voiding the current POLST form and writing/signing a new form, as well as giving the patient the updated form with instructions to destroy all older versions and putting the most current form in the patient's medical record (and archiving the old POLST form).

### Voiding a POLST Form.

A patient with capacity, or his/her valid surrogate when the patient lacks capacity, can void the form and request alternative treatment at any time. A form is generally voided when "VOID" is written in large letters across the form, but the process varies by state, particularly if there is a state registry to be notified.

### Should POLST forms be signed?

The POLST Paradigm Program requires health care professionals be trained to conduct shared decision-making discussions with patients and families so that POLST forms are completed properly. State law authorizes certain health care professionals to sign medical orders; the POLST form is signed by those health care professionals, who are accountable for the medical orders.

The POLST form may be signed by the patient with capacity or his/her valid surrogate when the patient lacks capacity, but such a signature is not required in all states. In Oregon, the patient or surrogate's signature is only recommended; in New York, the patient or surrogate only attests that the conversation has taken place.

The NPPTF encourages all states seeking endorsement to require a patient or surrogate's signature on the POLST form, but is it not a required form element for endorsement. Since traditional

medical orders are not signed by patients or surrogates, NPPTF's focus is on encouraging programs to design systems to ensure the conversation about patient's treatment options and goals has taken place.

#### Is POLST the same as an Advance Directive?

The POLST form is <u>not</u> intended to replace an advance directive document or other medical orders. The two documents differ, as will be discussed below, but they ideally work together. In short, the POLST turns the patient's wishes expressed in an advance directive into action as a medical order.

### a. Key Differences

While all competent adults - regardless of health status - should have an advance directive, not everyone should have a POLST. As discussed above, POLST is for a very specific patient population. The POLST form is a set of medical orders, similar to the do-not resuscitate (allow natural death) order. POLST is <u>not</u> an advance directive. POLST does not substitute for naming a health care agent or durable power of attorney for health care. The differences are best presented in a chart:

POLST Form	Advance Directive
Medical Order	Legal Document
Immediately takes effect	Needs interpretation and discussion to be effective
Communicates medical treatments specific to patient's current state of health  Does <u>not</u> appoint a health care surrogate or representative	Communicates general wishes about medical treatments in future states of health Appoints a health care surrogate or representative
Easy to locate (as medical order is in medical record). May also be in a registry. Most current version can be made easily available in medical record.	Generally not available when needed (patients have onus to ensure a copy is in the medical record and/or given to family to provide at time it is needed). Patients also have the onus to provide new copies when updating the document.
For those with advance illness or frailty- at any age	All competent adults over 18 should have (or whatever age of majority is in specific state)
Signed by health care professional (state law dictates which professionals may sign medical orders)	Signed by individual, his/her health care surrogate or representative, possibly by witnesses and possibly requires notarization (depends on state law)

For healthy patients, an advance directive is an appropriate tool for identifying a surrogate decision-maker and making future end-of-life care wishes known. Advance directives are generally completed when an individual is unaware of what disease or medical issue they may have in the future so it only provides general guidance. Further, it is a legal document requiring interpretation and, because of that, it does not give directions in the field during an emergency.

Conversely, the POLST <u>is</u> a medical order. POLST takes effect as soon as it is signed by the health care professional and gives orders to others professionals, including emergency service personnel, which can be acted on. It is only when a patient is diagnosed with a serious advance illness that a POLST form would be appropriate. For these patients, their current health status indicates the need for standing medical orders for emergent or future medical care and they are able to make decisions about their care knowing their specific diagnosis and prognosis.

POLST orders are more easily located in an emergency. Further, having a single form for medical orders provides consistency that allows emergency service personnel to follow the medical orders in the field because they know where to look for specific information in an instant (this is also helped by the NPPTF encouraging all states to have all medical orders on the front page of the POLST form). This consistency then allows emergency service personnel to incorporate a procedure for using POLST in their scope of practice. Additionally, several states, including Oregon, West Virginia, Idaho, Utah and New York, have registries for POLST forms, ensuring that emergency personnel and health care professionals know the treatment wishes of their patients during an emergency.

While the POLST Paradigm Program supports the completion of advance directives, clinical experience and research demonstrate that these advance directives are not sufficient alone to assure that those who suffer from serious advanced illnesses will have their preferences for treatment honored unless a POLST form is also completed. Max's story can serve as an illustration. Max's wife, Suzanne, shared his story with POLST this year; his story exemplifies the differences between advance directives and POLST and explains why POLST is necessary.

Max was born and raised in rural Oregon; he was a devoted father and doting grandfather, as well as a gifted athlete. He was a champion squash player, who loved to play golf, hunt and fish. His active lifestyle was dealt a life-changing blow around the time of his 75<sup>th</sup> birthday when he received the sobering diagnosis of aortic stenosis. Open heart surgery was his only treatment option, and the alternative was an increasingly frail state of health as the valve slowly closed. He thought deeply about his choices, especially given his other health problems. And the conclusion he reached was crystal clear: he did not want the surgery.

Although he loved technology, and had embraced it in his life's work, he was, according to his wife Suzanne, "a man of nature." He was adamant that he wanted his life, and death, to unfold naturally—without tubes or machines. So, with great care, he completed an Advance Directive to

document his end-of-life wishes, which he then shared with his family. He took comfort in the fact that his wish for a peaceful, natural death was clearly documented in an Advance Directive.

Suzanne and his family knew what he wanted and were comfortable with his decision. They knew he believed in the quality of life and had thought about it carefully, based on who he was and how he wanted to live out his days.

Sadly, this careful planning was not enough. Five years later, when Max collapsed from heart failure while playing golf on Mother's Day, his strongly-held wishes could not be honored. His Advance Directive, completed with such care and intention, did not serve as the medical orders needed to direct his care in this emergency situation. Max had just hit a good drive off the first fairway when his heart gave out. An ambulance was called to the scene and, when Suzanne arrived about 15 minutes later, she was deeply disturbed by what awaited her.

Emergency medical personnel were clustered around her lifeless husband, doggedly performing CPR in an attempt to revive him. She realized with horror that this was exactly what Max had most wanted to avoid. She begged them to stop, telling them that she had his Advance Directive in her purse. But they kept going. And she looked around, seeing all these people coming to see what was going on. And she felt even worse, knowing that Max—who was a very private man—would not have wanted this at all. He would have hated it.

In a medical emergency, EMTs have no choice but to do everything possible to save a life unless they have *medical orders* to the contrary. The POLST form provides the medical orders necessary to turn patients' wishes about the treatment they do and do not want into action. The advance directive is not even reviewed until Max is at the hospital.

Max's death would have been very different if the EMTs responding to his collapse had had a POLST form to direct the course of his care. He would have been allowed the dignified natural death he deeply desired. And his family, in their grief, would have had the comfort of knowing that his wishes had been both honored and respected.

# How do POLST and Advance Directives work together?

Patients with decision-making capacity can modify their POLST at any time to reflect changing circumstances—for example, when treatment has been initiated and more medical information becomes available regarding diagnosis, prognosis, or potential outcomes, the patient's goals and preferences may change. If the patient becomes incapacitated, the advance directive plays an important role in developing goals for care consistent with the patient in his/her new state of health. The surrogate identified by the patient in his/her advance directive would participate in either initiating a POLST or updating POLST orders in a manner consistent with the patient's preferences as the patient's health status changes.

# What Is the National POLST Paradigm Task Force (NPPTF)?

The NPPTF was convened in September 2004 to establish quality standards for POLST forms and programs and to assist states to develop such programs. The NPPTF includes one representative chosen by each state endorsed by the NPPTF.

### Goals of the NPPTF

In the early 1990s, the POLST Paradigm Program was developed to improve patient care and reduce medical errors by creating a system that identifies patients' wishes regarding medical treatment and communicates and respects them by creating portable medical orders. The system focuses on a growing segment of the United States population, those seriously ill patients with advanced, chronic progressive illness. While the NPPTF supports the completion of advance directives, clinical experience and research demonstrate that these advance directives are not sufficient alone to assure that those who suffer from serious, advanced, progressive chronic illnesses will have their preferences for treatment honored unless a POLST form is also completed.

A key component of the system is thoughtful, facilitated advance care planning conversations between health care professionals and patients and those close to them to determine what treatments patients do and do not want based on their personal beliefs and current state of health. In these conversations patients are informed of their treatment options and, if they wish, their health care professional completes a POLST form based on the patient's expressed treatment preferences.

A number of states have implemented the POLST Paradigm, and most others have expressed interest in doing so. POLST research shows that POLST use results in treatment consistent with patients' wishes more than 90% of the time, significantly reduces unwanted hospitalizations, and decreases medical errors.

The NPPTF is continuing to conduct research and develop quality measures to further assess the impact of the POLST Paradigm Program on patient outcomes. The goal of the NPPTF is to assure that the wishes of those with advanced illness and frailty are elicited, recorded and honored.

Overall, the NPPTF is dedicated to overseeing the success of the POLST Paradigm in every state and to establish clear tenets of the POLST Paradigm Program. Through its various committees, the NPPTF mentors developing states, reviews and approves (or denies) endorsement and mature status applications, and advises on communication, research and registry efforts.

#### How does POLST develop in the various states?

POLST has developed in states primarily through a grassroots approach, such as in Oregon, or through legislation or regulation. Current legislation in the states can be located in the legislative

guide created by the ABA Commission on Law & Aging. Development of the first twelve states adopting can be found in the AARP Public Policy Institute Research Report entitled "Improving Advanced Illness Care: The Evolution of State POLST Programs" (see Resources).

### What is the current status of the POLST Paradigm Program?

The NPPTF categorizes states based on their development status.

- (1) <u>States With Contacts</u>. When states are exploring the development of a regional or statewide POLST Paradigm program they can formally connect with the NPPTF. This level is for states not yet ready to complete the Developing POLST Paradigm documentation but who would like to participate in the National POLST Paradigm Program (e.g., receive emails from the national office, attend various education sessions put on by the National Office or the NPPTF, etc.). Oklahoma and Arkansas are currently in this category.
- (2) <u>Developing States</u>. Programs are recognized by the NPPTF as "developing" when they have both: (1) submitted the Developing State Status Application form and (2) presented the state's POLST form and progress to the NPPTF's Developing State Assistance Committee. Developing POLST Paradigm Programs may be at various stages of development, ranging from the initial design of a POLST form to active usage of POLST forms, but are working towards the goal of implementing the POLST program statewide. In general, programs at this step are starting to contemplate addressing all Seven Core Elements of Sustainability (Attachment 5). There are currently 22 Developing States: Arizona, Connecticut, Florida, Illinois, Indiana, Iowa, Kansas, Kentucky, Maine, Michigan, Missouri, Nevada, New Hampshire, New Jersey, New Mexico, North Dakota, Ohio, Rhode Island, South Carolina, Virginia, Vermont and Wyoming).
- (3) Endorsed States. The NPPTF will endorse state POLST programs when they have developed and implemented a POLST program and form meeting the NPPTF standards (See Request for Endorsement Status Form, Attachment 6). Endorsed programs are statewide or regional POLST programs that have become standard components of advance care planning in their location. These programs have addressed legal and regulatory issues associated with POLST, and have developed strategies for ongoing implementation and quality assurance. There are currently 14 endorsed states: California, Colorado, Georgia, Hawaii, Idaho, Louisiana, Montana, New York, North Carolina, Pennsylvania, Tennessee, Texas, Utah, Washington, and Wisconsin, however, Wisconsin is only regionally endorsed.
- **(4)** Mature States. Mature status is the highest level of endorsement by the NPPTF and is reserved solely for states with statewide POLST programs that, among other requirements (see Request for Mature Program Status Form, Attachment 7) are the standard preferred

method of advance care planning for persons with advanced illness or frailty. Mature POLST programs are used by 50% or more of hospitals, nursing homes, and hospices in each region (as defined by established criteria such as EMS, Department of Health, or the Dartmouth Atlas) of the state. These programs are actively gathering data for quality assurance programs and have considered centralized POLST databases. There are two states with Mature Program status: Oregon and West Virginia.

- (5) <u>States with Programs that do not conform to POLST Requirements</u>. There are some states that have developed POLST-like programs that, either due to how the program was implemented, the development of the form, or for legislative reasons, will not be endorsed by NPPTF in their current form. There are four currently identified:
  - a. Minnesota: Currently their form expressly states 911 should not be called when a patient's POLST orders are for "Comfort Measures Only". This violates the tenet of the POLST Paradigm Program that comfort measures are always provided to the patient; Minnesota's form overlooks instances where a patient cannot be provided comfort care in his/her current location. For example, if the patient falls and breaks a bone at home, it is unlikely their comfort can be adequately addressed in that location and it is likely the patient must go to the hospital for treatment to control their pain.
  - b. <u>Maryland</u>: Legislation going into effect this year requires POLST forms be completed for all patients except those in three limited categories. Their program violates the POLST Paradigm's tenant that a POLST is always voluntary.
  - c. <u>Delaware</u>: This program requires a patient be diagnosed as terminal before a POLST can be completed. Focus groups have shown that patients find the term "terminal" offensive. This program is too narrow in limiting the patient population that can access POLST; the target POLST population includes those patients where his/her health care professional would not be surprised if the patient died within the next year.
  - d. <u>Massachusetts</u>: The current form does not include the Section B discussed in Section 2(a) above but, instead, has a variety of questions. This lack of structure in the form causes confusion and lacks clarity.

Since this is a relatively new distinction, the NPPTF is working to evaluate other states currently in the "Developing State" category in light of recent legislation or form development. It is important for the NPPTF to clarify this category as the principles are important to the program; only mature and endorsed states should be used as examples of the POLST Paradigm Program.

We currently do not have contact with five states: Alabama, Alaska, Mississippi, Nebraska, and South Dakota.

#### What Are the Benefits of POLST?

POLST improves the quality of patient care and reduces medical errors by creating a system that identifies patients' wishes regarding medical treatment and communicates and respects them by creating portable medical orders.

A 2010 study by Susan Hickman in the *Journal of American Geriatric Society* showed that there was a reduction by 67% of medical interventions unwanted by the patients (mainly emergency room visits and hospitalizations) for patients with POLST forms with orders for Comfort Measures Only by compared with POLST orders for Full Treatment and 59% less than traditional Do-Not-Resuscitate orders. In short, POLST orders for Comfort Measures Only reduces hospitalization, readmissions and emergency room visits, as well as reducing care patients do not want to receive.<sup>3</sup>

#### What is needed for POLST to be successful?

Although it is a state effort, a uniform standard for electronic medical records should be a requirement that all EMR systems be designed in ways that POLST orders, as well as advance directives, be found quickly so they are easily accessible during an emergency. EMR systems are complicated and while a document may be "in the record" it may not be easily located. For documents that may be urgently needed—in order to ensure a patient's autonomy is respected—the NPPTF strongly recommends POLST forms be in a unique field/tab that can be accessed instantly, ideally in a single click.

#### What else is it important to know about POLST?

POLST orders honor patients following their religious values. For example, the POLST form allows Catholics to make decisions consistent with the United States Conference of Catholic Bishops *Ethical and Religious Directives for Catholic Health Care Services*, 5th ed. (2009) and ensures that those decisions will be honored in an emergency and across care transitions.

In general, the POLST form enables physicians to order treatments patients want and to direct that treatment that patients would not want, including those a patient and his/her health care professional would consider "extraordinary" and excessively burdensome. Further, the POLST form requires that "ordinary" measures to improve the patient's comfort and food and fluid by mouth, as tolerated, are always provided. The POLST form is actionable and prevents initiation of care the patient does not want and that the patient considers disproportionately burdensome, extraordinary treatment.

POLST orders record patient wishes to have or limit treatment but it is never the intent for the orders to be written with the goal of hastening death. POLST recognizes that allowing natural death to occur is not the same as intentionally shortening life. Some patients near the end of their lives

wish to stop treatments they find burdensome and have the primary focus of the care on their comfort. For these patients, POLST orders for Comfort Measures Only document their wish to step aside from medical treatments and allow nature to take its course. Comfort Measures Only is sometimes referred to as "Allow Natural Death".

In Oregon all of the hospitals, including the Catholic health systems, participate in the POLST program and use POLST orders to record the wishes of some of those with advanced serious illness under their care. For those patients desiring Comfort Measures Only, the POLST form documents orders to refuse treatments the patient finds overly burdensome in the advanced stage of their illness.

This is in stark contrast to physician-assisted suicide. Not a single Catholic hospital participates in the Oregon Death with Dignity Act, which is the deliberate hastening of death. Though this Act and POLST both came to fruition first in Oregon, there is no relationship between them. The POLST Program is completely separate from "death with dignity" and POLST forms do not allow orders to be written for medication with the goal of hastening death.

### What other resources are there regarding POLST?

The National POLST Paradigm website (www.polst.org) has additional information, including a variety of videos, POLST forms and educational materials, FAQs and resources. It has citations of the research done about or related to POLST and provides materials for states participating in the POLST Paradigm Program, such as the POLST Quality and Research Toolkit (PQRsT). This toolkit was designed to facilitate the study and improvement of POLST programs through data collection and analysis. The PQRsT consists of 30 instruments that have been created to study POLST for research or quality improvement projects, along with related research materials. POLST programs and researchers who have studied POLST programs have generously shared the instruments in the PQRsT in order to benefit POLST programs nationwide. Each instrument is paired with a summary, which provides more information on utilizing the instrument in data collection.

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<sup>&</sup>lt;sup>1</sup> POLST is known by different names in different states, including MOLST (Medical Orders for Life-Sustaining Treatment), MOST (Medical Orders for Scope of Treatment), POST (Physician Orders for Scope of Treatment), LaPOST (Louisiana Physician Order for Scope of Treatment), COLST (Clinician Orders for Life-Sustaining Treatment), IPOST (Iowa Physicians Orders for Scope of Treatment), SMOST (Summary of Physician Orders for Scope of Treatment), TPOPP (Transportable Physician Order for Patient Preference), and SAPO (State Authorized Portable Orders). For simplicity, the term POLST is used when referring to POLST Paradigm forms or programs in general.

<sup>&</sup>lt;sup>2</sup> POLST Request for Endorsement Program Status Form; Item 9 under "Form Information".

<sup>&</sup>lt;sup>3</sup> Hickman, Susan E. et al, (2010). "A Comparison of Methods to Communicate Treatment Preferences in Nursing Facilities: Traditional Practices Versus the Physician Orders for Life-Sustaining Treatment Program." *Journal of the American Geriatric Society* 58:1241–1248.

# Throwing Out the Baby with the Bathwater!

Although we had not originally planned to do so, "From the Field" in this issue of Health Care Ethics USA is totally devoted to POLST. This decision was prompted primarily by the publication of a "White Paper" in the May, 2013 issue of Linacre Quarterly that has been widely disseminated, including among the nation's bishops.1 There are also some indications that the article is serving as the basis and inspiration for letters to bishops urging them to oppose POLST. Needless to say, this could have a direct impact on Catholic health care. As reported in previous issues of HCEUSA, other articles critical of POLST have likely influenced opposition to POLST by church leaders in at least two states (see Fall, 2010, pp. 27-29; Winter, 2012, pp. 30-35; Spring, 2012, pp. 40-48; Fall, 2012, pp. 23-34).

This issue's "From the Field" includes a detailed analysis and critique of the *Linacre Quarterly* article by CHA ethicist, Fr. Tom Nairn, OFM, Ph.D. Our hope is that this critique will be helpful to our members and others in responding to queries about the *Linacre Quarterly* article. We are also including a Q & A about POLST that not only provides an excellent overview of POLST and how it works, but also addresses some of the concerns raised with regard to POLST. Hopefully, this too will be beneficial by providing a more objective presentation of POLST.

Our purpose here is neither to advocate for POLST nor to suggest that POLST is an ideal mechanism or perfect in its current form. There is undoubtedly room for improvement in many POLST forms across the country, as the Linacre Quarterly article points out, and possibly even in the POLST paradigm itself. POLST is an attempt to deal with several serious problems with end-of-life care. It is a tool. Whether or not this tool is successful in addressing these challenges, however, should be judged primarily from the experience of those who employ POLST—patients, surrogates, families, and clinicians. They are in the best position to judge whether POLST works, where it can be improved, and to what unforeseen consequences it might inadvertently contribute, if any. Experience and data drawn from experience should be the basis for any assessment of POLST.

Regrettably, the *Linacre Quarterly* article is not grounded in the broad-based experience of those who employ POLST. It ends up being based on some serious misunderstandings of POLST, generalizations, misquoting of published studies, hypotheticals, and insinuation. For example, early in the article the authors write: "[T]he form is immediately invested with the status of an actionable medical order, without regard to patient decisional capacity" (italics added).2 The latter is simply not true. Or, "we believe that the use of POLST forms will create unacceptable risks from both the perspective of good medical decisionmaking and good ethical decision-making.

...[T]he benefits will be grossly outweighed by the harms and abuses that will result from the use of the POLST form and the campaign to promote it."3 POLST has been operative in several states for quite some time. What is the empirical evidence for the harms and abuses? And here it is not sufficient to point to one or two examples, as the authors are prone to do; rather, one must demonstrate widespread harms and abuses. If we abandoned everything because of one or two harms or abuses, nothing would survive. This type of generalization is unacceptable. Or, "The forms are completed prior to the time that many people know the exact nature of their conditions or the range of reasonable treatment options."4 This statement reflects a serious misunderstanding of POLST and how it works. Examples could easily be multiplied, but just one more. The authors cite four foundations that have provided financial support for promoting POLST and go on to say, "these same foundations also have provided significant funding for right-todie-organizations. ... Perhaps, then, it is not coincidental that POLST programs are strongly supported by right-to-die coalitions and some palliative care organizations."5 The insinuation here obviously is that POLST is associated with efforts to promote assisted suicide (and, sadly, that palliative care is associated with the right-to-die). One of the authors of the Linacre article elsewhere has made an explicit connection between POLST and assisted suicide and euthanasia. This is inference. Where is the concrete evidence? Such an insinuation not only casts

POLST in a negative and dangerous light, but implicitly questions the integrity of clinicians across the country who are supportive of and employ POLST. It also implicitly casts aspersions on Catholic health care and its faithfulness to the Catholic tradition in end-of-life matters. There is much more, but that will be left to Fr. Tom Nairn's analysis.

Unfortunately, the *Linacre* article together with opposition to POLST by two State Catholic Conferences have led to a blog on a well-known and widely-used bioethics website titled "Dangerous Catholic Attack on POLST" (www.bioethics.net/2013/07/dangerouscatholic-attack-on-polst/. While the author does offer some qualifications and acknowledges that Catholic opposition to POLST is not monolithic, one could come away with the impression that, generally speaking, Catholicism opposes POLST. And it's quite easy to jump from that to the conclusion that Catholics oppose efforts to achieve good end-of-life care.

Along those lines, sadly, an article recently appeared in *Ethics and Medics* ("The Rise of Stealth Euthanasia," 38, no. 6 [June 2013]: pp. 1-3) that claims that "many hospice and palliative care physicians are urging, and actually performing, euthanasia by stealth. ... It is horrifying that health care professionals—those to whom we entrust our lives—intentionally hasten death while pretending to be providing appropriate end-of-life care." Hastening of death occurs, according to the authors, by using opioids and

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palliative sedation to intentionally kill patients under the guise of double effect.

The authors also claim that The National Hospice and Palliative Care Organization, "the leading trade organization for this industry, is the actual legal and corporate successor to the Euthanasia Society of America." They observe: "Indeed, the culture of death has deeply infiltrated the hospice and palliative care industry! Despite this, *some* health care professionals courageously remain faithful to the original mission of providing care until the natural end of life of a patient" (italics added).8

Is it possible that some physicians are intentionally hastening death? Of course. Is it possible that this is occurring in hospice and palliative care? Yes. Is this commonplace in hospice and palliative care? There is no evidence that it is widespread and the authors do not offer any such evidence. They are making serious, damaging claims that are empirically unsubstantiated as to the widespread nature of these abuses and, in so doing, they poison the waters. They create suspicion that can easily begin to undermine the development and sustaining of palliative care programs and the growing acceptance of hospice by physicians and the public, and thereby harm the advances that have been made in end-of-life care. POLST, hospice and palliative care are all attempts to improve end-of-life care (though palliative care is not limited to terminal illness), to address and alleviate the very factors and symptoms that make death even more

dreaded and difficult, and that make assisted death appealing to many. Those who undermine efforts to improve care at the end of life are playing into the hands of proponents of assisted suicide and euthanasia. Instead of throwing out the baby with the bathwater, they would do well to attempt to correct shortcomings, misunderstandings and abuses in a more focused, nuanced and even-handed manner.

R.H.

<sup>&</sup>lt;sup>1</sup> Christian Brugger, Louis Breschi, Edith Mary Hart, et al., "The POLST Paradigm and Form: Facts and Analysis," *Linacre Quarterly* 80, no. 2 (May 2013): 103-138.

<sup>&</sup>lt;sup>2</sup> Ibid., p. 105.

<sup>&</sup>lt;sup>3</sup> Ibid.

<sup>&</sup>lt;sup>4</sup> Ibid., p. 114.

<sup>&</sup>lt;sup>5</sup> Ibid., p. 107.

<sup>&</sup>lt;sup>6</sup> Ralph Capone, Kenneth Stevens, Jr., Julie Grimstad, and Ron Panzer, "The Rise of Stealth Euthanasia," *Ethics and Medics* 38, no. 6 (June 2013): 2.

<sup>&</sup>lt;sup>7</sup> Ibid.

<sup>8</sup> Ibid.

# Of Note

# The Requirement of Health: How Companies Could Discriminate

Companies are looking to reduce health insurance expenses through creating wellness programs to foster healthy employees. Some programs consist of employees attending wellness classes while others require physical measurement of employees and still others a combination of both. Gioia Zucchero presents a question: Are wellness programs discriminatory? CVS Caremark's health policy determines "healthy" people through the measurements of weight, body fat percentage and glucose level. Zucchero finds this troubling. "Taking all three metrics together, it's still not possible to make a determination about someone's health based on these basic measurements alone." Requiring personal information is not discriminatory but the discrimination lies in "penalizing an employee who yields 'unhealthy' numbers, either simply because they are deemed unhealthy or because the unhealthy employee chooses not to participate in the subsequent 'intervention' program." Zucchero concludes that "to penalize someone on the basis of correlation without causation is discriminatory." (Gioia Zucchero, www.bioethics.net, March 27, 2013)

# E.R.s Account for Half of Hospital Admissions, Study Says

A report by the RAND Corporation, a nonprofit research group, found that the increase in hospital admissions between 2003 and 2009 was almost exclusively a result of an increase in patients admitted through the emergency room. Dr. Arthur L. Kellermann, a study author, notes that the role of the emergency room has expanded to serve as a place for patients to go on evenings and weekends to receive "complex, time-efficient diagnostic workups." With rising numbers of admissions some question if the emergency room is the best place to be making decisions regarding admissions. "Patients may benefit from the speed and thoroughness of the diagnosis taking place in the emergency room ... but the expense could be much higher, and emergency physicians may be too eager to order costly tests." In contrast, the report also found reasons to believe that emergency physicians are good at avoiding unnecessary hospitals admissions. (Reed Abelson, *The New York Times*, May 21, 2013)

# Stem Cells Give Young Girl a New Life

Hannah Warren, a 2-year-old born with a defect known as tracheal agenesis, became the youngest patient to receive stem cell therapy. Hannah received a new windpipe

grown from stem cells extracted from her hip bone. The trachea is functioning well, and her recovery is being closely monitored. Stem cells divide quickly and are relatively unspecialized but can become tissue-specific making them the perfect tool in creating a new windpipe for Hannah. Recently stem cell therapy gained more public attention when NFL quarterback Peyton Manning received stem cell therapy in Europe to aid in nerve and bone growth in his neck. His therapy was unsuccessful but Hannah's treatment has more positive results. (Naomi Parikh, *The Examiner*, May 2, 2013)

[Editor's note: Hannah Warren died Saturday July 6<sup>th</sup> of lung complications following her second surgery. Her new windpipe was not a cause in her death.]

# Hundreds of Immigrants Are Being Deported from Their Hospital Beds

A recent report by the Center for Social Justice at Seton Hall Law School has uncovered new information concerning undocumented immigrants that seek care in American hospitals. The report found that in the last five years over 600 undocumented immigrants were deported from their hospital beds, even some while still unconscious. Lori Nessel, director for the Center for Social Justice, says that although hospitals call immigration authorities to handle the deportation of these patients, the authorities rarely take responsibility. The article author, Esther Yu-His Lee, notes that "medical

repatriation is an often necessary but cruel fact of life for hospitals that are facing financial cutbacks and the inability to be reimbursed." Without more federal funding, hospitals will continue to deport undocumented immigrants that need costly long-term care. (Esther Yu-His Lee, <a href="https://www.thinkprogress.org">www.thinkprogress.org</a>, April 23, 2013)

# Transplant Panel Orders Policy Review

In Philadelphia, a case of two children in need of a lung transplant has prompted the Organ Procurement and Transplantation Network to begin a yearlong review of current guidelines for allocation of lungs to children. The current policy says children under the age of 12 must wait for pediatric lungs to be available. The panel agreed to allow a case-by-case review in the interim. "All three committees at OPTN agreed that the underlying policy should not be changed in response to public pressure over individual cases. The question of how to best allocate scarce organs among terminally ill people is an ethically complex one." The families of the children, Sarah Murnaghan and Javier Acosta, sued the U.S. government and HHS Secretary Kathleen Sebelius to have their children placed on the adult donor list. U.S. District Judge Michael Baylson issued a temporary ruling in favor of the parents allowing Sarah to be placed on the adult donor list. HHS Secretary Kathleen Sebelius has received criticism for not waiving the policy for the sick children. In a Washington Times op-ed, Jane Orient called Sebelius "a death panel of one."

Some argue that if Sebelius would have allowed the exception to the policy she would have been seen as a "meddling government bureaucrat." (Brett Norman, *Politico*, June 10, 2013)

[Editor's note: Sarah Murnaghan received a set of adult lungs on June 12<sup>th</sup> which failed. She received a second set on June 15<sup>th</sup>.]

Students from the Center for Health Law Studies at Saint Louis University School of Law contributed the following items to this column. Amy N. Sanders, assistant director, Center for Health Law Studies, supervised the contributions of health law students Daniel J. Sheffner (JD anticipated May '14) and Courtney Thiele (JD anticipated May '14).

# Psychiatrists Introduce the DSM-5

The American Psychiatric Association (APA) released the newest edition of the "Diagnostic and Statistical Manual of Mental Disorders," the DSM-5, this May. Containing over 300 mental illnesses in just under 950 pages, the new DSM was 14 years in the making, with revisions of the DSM-IV beginning in 1999. However, the publication, the definitions contained in which designate what counts as a mental disorder, has been met with harsh criticism from many within the medical community. Dr. Thomas Insel, director of the National Institute of Mental Health, complained that the DSM-5 lacked validity because the vast majority of the mental illnesses listed in

the manual are derived from self-reported symptoms and subjective conclusions, instead actual science. The very subjective nature of mental illnesses make diagnostic foundation on biological or genetic bases impossible at present; however, this does not prevent psychotherapist Gary Greenberg from characterizing the DSM-5 as unreliable and "hopelessly and dangerously flawed." Critics are alarmed at what they see as an inflation of mental disorders which, they argue, makes it easier for one be diagnosed with a disorder. Equal alarm is generated by the removal of Asperger's syndrome from the list and other changes to autism spectrum disorders that will most likely result in fewer autism diagnoses. The APA plans to regularly update the DSM-5 in association with advancements in scientific research. (Sharon Begley, "Psychiatrists Unveil Their Long-Awaited Diagnostic 'Bible'," Reuters, May 17, 2013) http://www.reuters.com/article/2013/05/1 7/us-science-psychiatry-dsmidUSBRE94G04420130517.

### Obesity is Now a Disease

The American Medical Association (AMA) House of Delegates voted to recognize obesity as a disease. While the AMA's Council of Science and Public Health, the body tasked with reviewing the issue, counseled the House of Delegates against such a decision, the AMA nonetheless agreed with a resolution accepted by groups such as the American College of Cardiology and the American Association of Clinical Endocrinologists,

defining obesity as a "multimetabolic and hormonal disease" that leads to heart disease and Type 2 diabetes. Dr. Patrice Harris of the AMA believes that the organization's recognition of obesity as a disease will prompt physicians and other health care professionals to take the condition more seriously and will increase efforts directed at curbing rates of heart disease and Type 2 diabetes. Such increased attention will hopefully minimize the stigma associated with obesity. The AMA's decision may also increase access to care for obese patients by inducing insurers to improve reimbursement for obesity pharmaceuticals and medical procedures. Opponents of the classification argue that obesity is merely a risk factor, not an actual a disease. Despite the AMA's decision, there is no generally accepted definition of disease. (Andrew Pollack, "A.M.A. Recognizes Obesity as a Disease," The New York Times, June 18, 2013) http://www.nytimes.com/2013/06/19/bus iness/ama-recognizes-obesity-as-adisease.html?adxnnl=1&ref=health&adxn nlx=1371735772-GhaeWJbbQrv7r3FXoI+XHA.

# HPV Vaccine Decreases Infection Rate in Teens

A study published in *The Journal of Infectious Diseases* this year reported that the rate of infection in teenage girls of the human papillomavirus (HPV), a virus that infects nearly 19,000 women and 8,000 men each year in the U.S., has decreased by half thanks to a 2006 vaccine. HPV is a

leading cause of cervical cancer, a disease that claims nearly 4,000 deaths per year in the U.S. Despite its success, only about one-third of American girls have been introduced to the full vaccine, as opposed to the 80 percent vaccination rates in countries such as Britain, Denmark, and Rwanda. A March study published in the *Pediatrics* journal reported that 44 percent of American parents in 2010 intended to prohibit their daughters from undergoing vaccination, an increase from 40 percent in 2008. Worries that the vaccine's successes will contribute to unrestrained sexual behavior or even, according to U.S. Representative Michele Bachman (R-Minn.), that the vaccine has "dangerous side effects," are possible reasons for the low vaccination rates. However, public health officials are confidant that the HPV vaccine has no such detrimental effects. Cervical cancer is one of the most common cancers affecting women, and with nearly 79 million Americans currently infected with HPV, the HPV vaccine is, according to Dr. Thomas Frieden, director of the Centers for Disease Control and Prevention, "an anticancer vaccine," nothing more, nothing less.

(Sabrina Tavernise, "HPV Vaccine is Credited In Fall of Teenagers' Infection Rate," *The New York Times*, June 19, 2013)

http://www.nytimes.com/2013/06/20/hea lth/study-finds-sharp-drop-in-hpv-infections-in-girls.html?ref=health.

# Abortion Remains Election Issue for 2014

Abortion, ever a contentious and national issue since the U.S. Supreme Court's 1973 Roe v. Wade decision, has yet again been thrust to the forefront of American politics. Republicans throughout the country have proposed bills that would ban abortions after the 20th week of conception, mandate ultrasounds prior to receiving an abortion, and affect other wide-ranging measures. Forty-three new laws have been enacted this year alone by Republican state governments that regulate or restrict access to abortion. The Congress has also joined the fray with the U.S. House of Representatives passing a bill banning abortions after 20 weeks, even while *Roe* prohibits restrictions until "viability" (which has been determined to occur around 24 weeks). The increased attention may ensure a large turnout of social conservatives at the polls in the upcoming congressional and presidential elections, which can only serve to benefit Republicans. Democrats accuse Republicans of working to restrict women's constitutional rights all while ignoring the pressing economic difficulties affecting Americans. They believe that moderate voters will register their disagreement at the polls, perhaps even delivering the 18 seats needed to gain a majority in the House of Representatives in the 2014 congressional elections. However, whether the spotlight cast over the abortion debate will provide either party with a winning edge in the upcoming elections is uncertain: a Gallup

poll from last May reported that, although 49 percent of Americans believe abortion to be morally wrong, only 20 percent believe that it should be absolutely prohibited.

(Jennifer Agiesta & Gary Robertson, "Republicans Return Abortion to the Front Burner for 2014 Elections, Democrats See Gains as Result," The Associated Press/Washington Post, July 15, 2013)

http://www.washingtonpost.com/politics/f ederal\_government/republicans-return-abortion-to-front-burner-for-2014-elections-democrats-see-gain-as-result/2013/07/15/1baa1580-ed28-11e2-b46e-f15eec37b46c\_story.html.

#### No Patents on Human Genes

In a unanimous decision, the United States Supreme Court ruled that isolated human genes cannot be patented. This decision came in response to a challenge on the genetics company, Myriad's, patent on the BRCA1 and BRCA2 genes used to identify a genetic predisposition towards breast and ovarian cancers. Justice Thomas stated, "A naturally occurring DNA segment is a product of nature and not patent eligible merely because it has been isolated." Myriad, and consequently other companies invested in genetic research, did have a partial victory, however, as the Court simultaneously ruled that "complementary DNA," also known as cDNA, which is created in the laboratory, can be patented. This allows for genetic researchers to alter DNA and

still be able to patent the product of their work when something new is created. (Justices, 9-0, "Bar Patenting Human Genes, Adam Liptak," *The New York Times*, June 13, 2013) http://www.nytimes.com/2013/06/14/us/supreme-court-rules-human-genes-maynot-be-patented.html?hp&\_r=1&

# Study Finds Benefits in Delaying Severing of Umbilical Cord

A recent study involving 3,911 motherinfant pairs has found that delaying clamping the umbilical cord by at least a minute after birth "significantly improves iron stores and hemoglobin levels in newborns and does not increase the risks to mothers." This finding contrasts with current medical practice, which usually leads to clamping the umbilical cord less than a minute after the baby is born. This study found that infants who had delayed clamping showed much better iron levels up to six months after they were born. These babies also had higher birth weights, as they were able to recover some blood from their mothers through this procedure. Part of the reason for the standard practice of almost immediately clamping the umbilical cord after birth was out of fear for the health of the mother. Concerns regarding postpartum hemorrhaging, blood loss and reduced hemoglobin levels all contributed to this common practice. However, this study found these concerns unwarranted. Delayed clamping was not found to increase any risk for the mother, and with the exception of a slight increased risk of the baby becoming jaundiced, was found

to be very beneficial to the new baby's health. It is important to note this study did not include women delivering via cesarean section. ("Study Finds Benefits in Delaying Severing of Umbilical Cord," Catherine Saint Louis, *The New York Times*, July 10, 2013) http://www.nytimes.com/2013/07/11/health/study-endorses-later-severing-of-umbilical-cord.html?ref=health

### Stem-Cell Therapy May Cure HIV

Using adult stem-cells from a donor with genetic mutation resistance to the HIV virus, two Boston patients have been cured of HIV. After completing a treatment process of using stem-cell transplants, the HIV virus appears to have been eliminated, although doctors are continuing to follow-up with the patients for at least a year in order to be sure the virus does not resurface. After the patients had been off of their antiviral treatment for 15 and seven weeks, respectively, neither had any indication of reappearance of HIV. Because the cost of using stemcell treatment for HIV is still very expensive the treatment will not be widely available in the near future. However, as 34 million people worldwide are infected with HIV, implications of this discovery have the potential to profoundly impact many people once (and if) treatment becomes more widely available. ("Stem-Cell Therapy Wipes Out HIV in Two Patients," Ben Hirschler, Reuters, July 3, 2013)

http://www.reuters.com/article/2013/07/0 3/us-hiv-stemcells-idUSBRE9620IL20130703?irpc=932

## **RESOURCES**

# Select Resources on End-of-life Decisions and on POLST

"POLST: What It Is and What It Is Not," see <a href="https://www.polst.org">www.polst.org</a>.

"Religious Faiths and Cultural Heritages" at <a href="http://lhcqf.org/lapost-for-patients-a-families/resources/religiouscultural-information">http://lhcqf.org/lapost-for-patients-a-families/resources/religiouscultural-information</a>. This is a resource for patients and families on religious and cultural perspectives on end-of-life care.

Sabatino, Charles and Naomi Karp, "Improving Advanced Illness Care: The Evolution of State POLST Programs," Washington, DC: AARP Public Policy Institute, 2011. Available at <a href="http://www.aarp.org/ppi">http://www.aarp.org/ppi</a>.

"The Final Journey: Information from the Catholic Bishops of Louisiana on End-of-Life Decisions," at <a href="http://lhcqf.org/page-flip/The-Final-Journey/">http://lhcqf.org/page-flip/The-Final-Journey/</a>.

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Executive editor: Ron Hamel, Ph.D., CHA senior director, ethics

Associate editors: James DuBois, Ph.D., D.Sc., Mader Endowed Professor of Health Care Ethics and director, Bander Center for Medical Business Ethics, Albert Gnaegi Center for Health Care Ethics, Saint Louis University; Sr. Patricia Talone, RSM, Ph.D., CHA vice president, mission services; and Rev. Thomas Nairn, OFM, Ph.D., CHA senior director, ethics. Elliott Bedford, ethics fellow, Ascension Health, is editorial assistant. *The Theologian/Ethicist Committee serves as an advisory committee to the editorial board.* 

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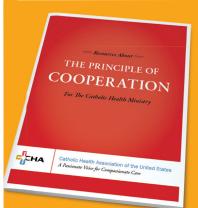
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