

# Health Care Ethics USA

A resource for the Catholic health ministry

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# A Catholic Case for Public Health

Michael Rozier, SJ  
 Boston College  
 Department of Theology  
 Chestnut Hill, Mass.  
[roziermd@gmail.com](mailto:roziermd@gmail.com)

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## Introduction

*“A man was going down from Jerusalem to Jericho, and fell into the hands of robbers who stripped him, beat him, and went away, leaving him half dead. Now by chance a priest was going down that road; and when he saw him, he passed by on the other side. So likewise a Levite, when he came to the place and saw him, passed by on the other side. But a Samaritan while traveling came near him; and when he saw him, he was moved with pity. He went to him and bandaged his wounds, having poured oil and wine on them. Then he put him on his own animal, brought him to an inn, and took care of him. The next day he took out two denarii, gave them to the innkeeper, and said, ‘Take care of him; and when I come back, I will repay you whatever more you spend.’ Which of these three, do you think was a neighbor to the man who fell into the hands of the robbers?” He said, “The one who showed him mercy.” Jesus said to him, “Go and do likewise.” (Luke 10:30-37)*

There are few stories in the Christian imagination more powerful than Luke’s Good Samaritan. And there are few injunctions more clearly lived out by the Catholic Church than going and likewise caring for the sick and suffering. The work done to care for the sick has a rich history in the church and is grounded in the desire to participate in the healing ministry of Christ. In this essay I intend, however, to show that there is an unexplored case to be made for the church’s activity in public health, or population health. Although

complementary in many ways, I intentionally juxtapose medicine and public health as ways to “go and do likewise” in order to emphasize the latter’s potential for fruitful ministry.

The distinction is not always perfect, but medicine focuses on treating individual patients who are already ill while public health focuses on preventing illness at the population level. The difference is not clean because physicians also attempt to prevent disease at the individual level or work with populations; and public health

attempts to bring communities from states of illness to health or work with individuals.<sup>1</sup> But the primary tasks persist. While medicine and public health obviously work together, in a context of limited resources—as health services always are—choices must be made about where to place emphasis. The tension between prevention and cure is unresolved in civil society,<sup>2</sup> and I believe the Catholic community should feel greater tension than it does with regard to where it places its resources.

As a relatively new discipline, public health often finds itself pushing against the established medical order, especially in the American context. First, medicine emphasizes disease diagnosis and treatment at the individual level while public health focuses on the population level. Therefore, medicine fits much more easily with the individualism and libertarian ethos of the United States. Second, the effects of medicine are more immediate and visible, with patients literally rising up from a hospital bed and walking home. Public health often requires long-term thinking and its effects are often the absence of an illness. With this, medicine has the advantage of tapping into our established empiricism and our growing need for immediacy. Third, medicine is increasingly dependent on technology, while public health employs behavioral, environmental, and policy changes that have less reliance on the newest advance. Once again, medicine wins in a society that believes salvation comes with the next discovery. Finally, medicine requires highly trained clinicians who create an almost-priestly class, with

knowledge and abilities upon which the faithful depend. Public health professionals, while professionally trained, do not have the same social status as physicians. Therefore, medicine has a more respected voice in the public square.

It may seem like I am presenting a facile dichotomy, but it is important to understand why medicine so dominates the public's imagination when it comes to use of health resources. It follows, of course, that because a large majority of resources are placed into medical care, a large majority of ethical and moral thinking, both within and outside of the church, has been directed toward it as well. Medical ethics, which arose from the tragedy of Nazi experiments during World War II, has decades of dedicated study while public health ethics is just building its foundations.<sup>3</sup>

### Emphasis on Medical Care

The Catholic presence in medical care is a line stretching from the healing ministry of Jesus to the robust national and international health systems operated today.<sup>4</sup> Early Christian deacons were to provide *hospitalitas*, a term that spoke to caring for another's deepest needs, including illness. Care centers were established in a variety of forms including inns for travelers, orphanages, and homes for the aged, all in the name of *hospitalitas*. But the modern hospital system appeared in its inchoate form with the advent of monasteries. The extensive monastery system that began with St. Benedict and eventually was found throughout Europe provided the necessary stability for

caregiving, became repositories of medical knowledge, and eventually became partners with civil institutions that were started by Christian governments. Although the Reformation and the rise of the nation-state changed the overall complexion of Catholic health care in Europe, the rise of religious orders devoted to health care and the missionary activity of the church around the world were vital to an ever-increasing presence of Catholic health care. In the United States, the dedication of women religious to personal care and their subsequent professionalization through specialized training led to an impressive system of Catholic hospitals. In 1915, members of the Sisters of St. Joseph and Fr. Charles Moulinier, SJ, founded the Catholic Hospital Association. The organization was subsequently renamed the Catholic *Health Association*, but its primary emphasis is still hospital administration.

The Catholic health care system has roots in the life and ministry of Jesus, grew up with Christian Europe, and is now a major influence in the United States and around the world. Catholic hospitals serve 15% of all patients in the United States<sup>5</sup> and it can be over 50% of all hospital beds in countries with little government health infrastructure, such as the Democratic Republic of Congo. In the United States alone, Catholic hospitals annually spend nearly \$100 billion on health care delivery.<sup>6</sup> Internationally, the figures, although certainly substantial, are almost impossible to ascertain because they flow out of so many different levels of the church – parishes, schools, dioceses, and hospitals.

So what are the reasons for continued engagement in health care? The short answer is the major sources of moral reflection: Scripture, tradition, human experience, and rational reflection. There are at least 18 healing miracles in the Gospels where Jesus gave sight to the blind (Matthew 9:27-31), cured the leper (Luke 5:12-16), or enabled the lame to walk (Mark 2:1-12). But as important as the example of Jesus himself is, the mission of those he sends out into the world is just as telling. “Whenever you enter a town and its people welcome you, eat what is set before you; cure the sick who are there, and say to them, ‘The kingdom of God has come near to you.’” (Luke 10: 8-9) In Scripture, curing the sick is not just a physical reality; it is a sign of God’s kingdom. It not only heals the body, but restores the soul and welcomes the cured back into the community. It is spiritual and social restoration as well as physical healing. Medicine’s rootedness in Jesus cannot be overstated for the Christian community. It not only authenticates the ministry throughout history; it has a powerful hold on the Christian imagination. It is impossible to imagine Jesus apart from his healing ministry and it would be equally difficult to imagine the church living out the fullness of its mission without doing the same.

Tradition also plays a strong role in Catholic health care. In addition to the storied history recounted above, many documents from the magisterium have lauded ministry in health care. In 1981, the United States Catholic Conference (now the USCCB) published *Health and*

*Health Care*, a pastoral letter that expressed their “full commitment to the Catholic health care apostolate and [their] encouragement of support of professionals in the health field.”<sup>7</sup> In 1994, the Pontifical Council for Pastoral Assistance published the *Charter for Health Care Workers*, where it states the work of health care “expresses a profoundly human and Christian commitment, undertaken and carried out not only as a technical activity but also as one of dedication to and love of neighbor.”<sup>8</sup> In addition to extolling the work of health care in general the magisterium has demonstrated a significant interest in particular aspects of bioethics, especially ethical questions that surround beginning- and end-of-life issues. It is clear that the magisterium sees the work of health care as essential to bolstering a culture of life.

Human experience and rational reflection are largely interconnected when considering the Catholic role in health care. The stories in Scripture and the magisterial teaching speak to ideas that transcend any particular religious tradition. We cannot enjoy the fullness of our humanity when we are sick. Our wellbeing depends, among other things, on our health. We know this to be true from lived experience, but many scholars make rational, normative claims about the essential dimension of health.<sup>9</sup>

Participation in health care, then, is a human activity that is aimed at producing a vibrant, flourishing community. In addition, there are rational, selfish reasons to want people to be healthy rather than sick, including a healthy person’s ability to contribute to society and an economy.

With increasingly expensive technology, however, health care has needed to be tempered with versions of cost-benefit analysis. Catholic health care is not immune to this challenge, but the difficulty of agreeing to a cost-benefit analysis when it comes to a human life should not be passed over quickly. Although not without its challenges, these sources point to a clear moral justification for Catholic participation in health care. However, the sources of moral reflection are less robust when it comes to public health.

### Emergence of Public Health

The history of public health is nearly as long as medicine, but is nowhere as storied.<sup>10</sup> Ancient Greece and Rome provide examples of efforts on food security, water potability, and sanitation, but with little knowledge of the natural history or transmissibility of diseases, there was little that could be done on a large scale to ensure the public’s health. We do not see the field of public health come into its own until the Industrial Revolution and the accompanying need for the sanitary movement which happened to be followed by the bacteriological era. The need to control disease as population densities increased was made possible largely because germ theory emerged as a way for scientists to identify pathogenic organisms. Biological advancement, accompanied by social movements to demand government action, brought public health into the modern era. And although there were individuals within the church who certainly helped advance public health

through the centuries, it would be incorrect to say that the church played a concerted effort in public health. Unlike medicine, where efforts by private institutions often precede governments, public health's original advance was most often shepherded by government action.

The rise in public health activities over the past several decades, especially in low resources settings where governments are unable to provide for public health needs, has slightly shifted that narrative. The AIDS crisis and its ability to raise awareness of related global health issues was the most significant factor in getting non-governmental organizations and faith-based organizations involved in public health. By looking briefly at the global burden of disease we might consider why public health has recently gained advocates.<sup>11</sup> When considering the top ten causes of loss of healthy life,<sup>12</sup> most of them – including diarrheal disease, cardiovascular disease, prematurity – are best solved by public health measures. We can provide antiparasitic medication to a village of children a dozen times over their childhood. Or we can provide the rotavirus vaccine and a source of potable water. We can try to treat perinatal infections with expensive medication. Or we can provide small kits to allow for clean umbilical cord care at birth. And even with historic efforts, every year we still have more people newly diagnosed with HIV in sub-Saharan Africa than new patients on anti-retroviral drugs.<sup>13</sup> In essence, we will never be able to *treat* our way out of these illnesses and into health. An analysis of the domestic

burden of disease would yield a similar conclusion.

There are examples of non-governmental actors in public health, such as Rotary International's near-heroic effort to eliminate polio through vaccination. Yet even though there are long-standing needs for water and sanitation, malaria prevention, and vaccination, very few private organizations are committed to public health in the way they have been committed to medical care. The tide is changing, but I do not believe the Catholic Church sees the full potential of embracing the work of public health. This is in part due to the existing commitments it has to medical care. But it is also because the sectors of sources for moral theology are much less obvious when it comes to public health than they are for medical care.

If a public health practitioner is looking to the Gospels to ground their work similar to resources found by doctors and nurses, he or she will be looking for quite some time. Perhaps something can be construed out of Luke 6:37-42 when Jesus calls to disciples to take the log out of their eye so that they can take the speck out of their neighbor's and they can both, therefore, avoid falling into the pit. Or perhaps Matthew 7:24-27, where the disciples are exhorted to build a house with a strong foundation so that it might withstand a future flood. Or maybe the Matthean parable of wise and foolish bridesmaids (25:1-13) conveys a message of public health, where those who are not prepared will not find the kind of life they are hoping for. But all of these examples limp

when compared to the many examples of healing found in the Gospels. Imagine how much less compelling the parable of the Good Samaritan would be if it were characterized by public health.

A man was going down from Jerusalem to Jericho, and arrived without incident. This is because Jesus provided the necessary mental health services for the men who would have otherwise beaten the man on his journey. Go and do likewise.

Or

A man was going down from Jerusalem to Jericho, and was approached by a band of robbers who needed money to care for their sick families. But the man, a passing Levite, a priest, a Samaritan, and an innkeeper were all able to sit down with the robbers. They found some of them employment that carried health insurance and others they enrolled in a social safety net. Go and do likewise.

Obviously, the parables of public health do not have the same ring as the original.

The source of tradition is slightly more fruitful. The *Charter for Health Care Workers* has a section on prevention in which it states,

Safeguarding health commits the health care worker particularly in the area of prevention. Prevention

is better than cure, both because it spares the person the discomfort and suffering from the illness, and because it spares society the costs, and not only economic costs, of treatment. ... But [preventive intervention] needs a concerted effort from all sectors of a society. Prevention in this case is more than a medical-health action.<sup>14</sup>

In their statement on health care, the United States bishops also speak of “touching the social conditions that hinder the wholeness which is God’s desire for humanity” and our duty to address threats to health that are “rooted in the structures of society.”<sup>15</sup> Although always stated in the context of medical care, these statements show appreciation for the work of public health and the necessity to think more broadly than delivering medical care as a way to promote God’s desire for full human flourishing.

Human experience and rational reflection are once again considered together. If pressed, people would probably not name public health as a discipline they highly value; certainly, it would fare worse than medicine. But if we ask about the outcomes of public health measures – clean air and water, vaccinated children who don’t get sick, ability to work in a safe environment, possibility of growing old while still healthy – these are all aspects of people’s lives that they would not want to do without and are only made possible by public health efforts. If given a choice of staying healthy or getting sick and being cured, there is no doubt that

people would choose to stay healthy. If one had the choice of his or her neighbor staying healthy or the neighbor getting sick and being cured, he or she would obviously prefer the former. Many people point to the cost-savings of public health but this is not as solid an argument as one intuitively might think. The United States spends 8-9% of health expenditures on prevention,<sup>16</sup> but there is little evidence that more preventive measures would bend the cost curve downward.<sup>17</sup> Rather, the main reason for investing in prevention is its ability to give people fuller, healthier lives than they would otherwise have.

### A Necessary Investment

Once placed on Catholic health care's radar, it will not take long to embrace the need for deeper ethical reflection on public health. For example, Ron Hamel has already noted the potential of population health and the way principles of Catholic social teaching—specifically inherent dignity of all persons, solidarity, common good, stewardship, justice, and participation—provide an already strong foundation for ethical reflection. For example, regarding the common good he writes, “what we are seeing in the development of ACOs and medical homes is the creation of structures that promote the good of individuals as well as the well-being of an entire given population.”<sup>18</sup> One of the primary challenges will be how to respect the inherent dignity of the individual while giving greater consideration to the individual's social context. The triumphalism of autonomy in secular bioethics was, in my opinion,

never particularly Catholic to begin with. Therefore, Catholic scholars could easily lead the way in the shift toward balancing individual, clinical considerations with appropriate demands that come with being part of a larger society.

One example of Catholic wisdom is found in a reflection on charity and justice as they are lived out in medicine and public health. Charity has many meanings but it is most clearly illustrated in the corporal works of mercy such as feeding the hungry, clothing the naked, and visiting the sick. It is providing immediate care for those in need, much like the Good Samaritan. Justice, also a multivalent concept, is a virtue but more grounded in logic; it is ensuring each one is given his or her due. Moreover, it is often characterized as *social* justice and therefore speaks to social structures in which we are all embedded. It would be easy to characterize medicine as an act of mercy and public health as act of justice and view them as competing with one another. Yet according to the U.S. bishops, “an essential element of our religious tradition ... is that the works of mercy and the works of justice are inseparable.”<sup>19</sup> Pope Benedict XVI also writes about this inseparability quite clearly in *Caritas in veritate*.

If we love others with charity, then first of all we are just towards them. Not only is justice not extraneous to charity, not only is it not an alternative or parallel path to charity: justice is inseparable from charity, and intrinsic to it. Justice is the primary way of

charity or, in Paul VI's words, 'the minimum measure' of it ...<sup>20</sup>

The false notions of charity as providing medical care to the uninsured and justice as working for health insurance reform are insufficient to understand their truly complex, and interdependent relationship. When a Catholic hospital provides emergency care to an uninsured patient, I find it hard to label that as "charity care." Is that care not due to him by reason of being human? Is it not the minimum measure of what should be given? Or is it from the institution's gratuity? When a Catholic hospital donates unused supplies that would have been thrown away to an institution in the global south, is that charity or justice? And if a group of doctors and nurses travel to the country where several of the hospitals' certified nursing assistants were recruited from, is that charity or justice? I would say the reflex answer from most clinicians or administrators would be that it is charity. But I am not sure that such is true and it at least deserves greater reflection. It is certainly good work that flows from loving intention, but they might more properly be considered works of justice.

Greater attention to public health has the potential to strengthen Catholic identity in health care because of public health's emphasis on the poor and vulnerable, a principle that has consistently animated Catholic health care through history. Monasteries were run as charity hospitals and missionary activity regularly brought higher quality care to areas of the world than they otherwise would have had. And when Catholic hospitals were established

in the U.S., those with wealth and social support received care at home while the poor and abandoned went to these religious institutions. Nevertheless, Catholic health care must regularly reconsider the question of what the poor need most and how the church can best respond to those needs. In my opinion, this is best done by epidemiological data on disease burden as well as prioritizing interventions that have disproportionate benefits for the poor. The option for the poor is sometimes implicit because many population-level interventions have a greater benefit for the poor and vulnerable (i.e., the wealthy would find a way to secure healthy food, vaccinate their children, and procure preventive screenings even without public health efforts). And it is sometimes explicit, such as efforts to reduce health inequities. Participation in such public health activity, therefore, could only deepen the Catholic commitment to the poor.

Further involvement in public health will likely raise difficult questions for Catholic health care. For example, at the domestic level, do the poor need specialty and tertiary care centers or do they most need community health clinics? What most effectively alleviates the burden of disease borne by the poor? And at the international level, should we model outreach on the U.S. health care system or do we need to encourage preventive medicine aimed primarily at social determinants of health? I am obviously presenting an unattractive dichotomy. The poor deserve both. Nevertheless, while large, complex health systems (even considering a large amount of 'charity'

care), might be the traditional way Catholics engage in the ministry of health care, it may not be the best way forward— theologically or epidemiologically. I don't claim to have these questions answered; I only suggest they must be asked and public health helps us do so.

Several public health measures have made for high profile challenges with the Catholic Church.<sup>21</sup> These include: harm reduction strategies such as needle exchanges; the distribution of condoms specifically for disease prevention; vaccinations, including the HPV vaccine for a sexually transmitted infection as well as vaccines originally derived from cells of aborted fetuses. Involvement in public health will not be without ethical controversy, but neither has involvement in modern medicine. Therefore, if Catholic involvement in the field increases as I suggest it should, we will need to invest as heavily in theological reflection for public health as we have with medicine.

## Conclusion

The theological resources exist for defending a greater Catholic investment in public health. Resolving the tension of investment of limited resources for medicine and public health is not *either/or* but *both/and*. Medicine is clearly an extension of the healing ministry of Jesus and has strong moral foundations, yet the emergence of public health gives us the opportunity to re-think our engagement in health care and find a different balance between the two. My hope is that it is driven by epidemiological data and

embraces theological considerations well beyond beginning- and end-of-life issues. There are nearly eight decades of life in between those moments, much of it lost to preventable illness. I believe public health and its moral demands provide the most effective means of reclaiming this loss. The pressing question is whether we have the freedom and imagination to engage it as fully as it deserves.

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<sup>1</sup> Another useful way of making this distinction is describing 'levels of preventions', which Mary-Jane Schneider does well in *Introduction to Public Health*. Regarding lung cancer: primary prevention (the work of public health) is to discourage smoking; second prevention is to detect cancer through screening; tertiary prevention (the work of medicine) includes medical treatment of cancer patients.

<sup>2</sup> *Prevention vs Treatment: What's the Right Balance* by Halley Faust and Paul Menzel is a recent book that documents the challenge of this issue.

<sup>3</sup> "An Ethics Framework for Public Health" by Nancy Kass is one of the first attempts to articulate a unique approach to public health ethics and it was only published in 2001. "Medicine and Public Health, Ethics and Human Rights," by Jonathan Mann in 1997 is another early attempt at distinguishing public health ethics from medical ethics.

<sup>4</sup> The entirety of this paragraph is referenced from John Padberg, S.J., "Catholic Health Care: The Mission and Ministry," Vols. 1-4 *Parameters* 1983, 1-8.

<sup>5</sup> "Fast Facts," Catholic Health Association, accessed November 22, 2012, [http://www.chausa.org/Pages/Newsroom/Fast\\_Facts/](http://www.chausa.org/Pages/Newsroom/Fast_Facts/)

<sup>6</sup> Catholic Health Association, 2012.

<sup>7</sup> United States Catholic Conference, "Health and Health Care: A Pastoral Letter of the American Catholic Bishops," Nov. 19, 1981, 3.

<sup>8</sup> The Pontifical Council for Pastoral Assistance to Health Care Workers, "The Charter for Health Care Workers," Vatican City, 1995, 1.

<sup>9</sup> In addition to Martha Nussbaum's capabilities approach, Madison Powers and Ruth Faden articulate six dimensions of well-being in their book, *Social Justice: The Moral Foundations of Public Health and Health Policy*, which is a useful framework.

<sup>10</sup> The background for this paragraph is from Chapters 2, 6, & 7 in George Rosen, *A History of Public Health*, (Baltimore: The Johns Hopkins University Press, 1993).

<sup>11</sup> There are many ways to present the data for global burden of disease, but the most widely accepted is Disability-Adjusted Life Years. I have therefore chosen that as my reference point.

<sup>12</sup> World Health Organization, "Global Burden of Disease: 2004 Update," Geneva: 2004, 43.

<sup>13</sup> UNAIDS, "2012 UNAIDS Report on the Global AIDS Epidemic," Geneva: 2012, 8 & 50.

<sup>14</sup> The Pontifical Council for Pastoral Assistance to Health Care Workers, "The Charter for Health Care Workers," Vatican City, 1995, 50-58.

<sup>15</sup> United States Catholic Conference, "Health and Health Care," 1981, 6-7.

<sup>16</sup> Miller, G., Roehrig, C., Hughes-Cromwick, P., and Lake, C., "Quantifying National Spending on Wellness and Prevention," in *Advances in Health Economics and Health Services Research: Beyond Health Insurance, Public Policy to Improve Health*, Emerald Group Publishing Limited, 19 (2008): 1.

<sup>17</sup> Louise B. Russell, "Prevention vs. Cure: An Economist's Perspective on the Right Balance," in *Prevention vs. Treatment: What's the Right Balance?*, edited by Halley S. Faust and Paul T. Menzel (Oxford: Oxford University Press, 2012), 71.

<sup>18</sup> Ron Hamel, "Catholic Identity, Ethics Need Focus in New Era," *Health Progress* 94;3 (May-June 2013), 87.

<sup>19</sup> United States Catholic Conference, "Health and Health Care," 1981, 6.

<sup>20</sup> Pope Benedict XVI, *Caritas in veritate*, 2009, 6.

<sup>21</sup> Nuala Kenny, "Cure vs. Prevention: Catholic Perspectives," In *Prevention vs. Treatment: What's the Right Balance?*, edited by Halley S. Faust and Paul T. Menzel (Oxford: Oxford University Press, 2012), 302-305.

## Works Cited

Pope Benedict XVI. "Caritas in veritate." Accessed November 22, 2012.

[http://www.vatican.va/holy\\_father/benedict\\_xvi/encyclicals/documents/hf\\_ben-xvi\\_enc\\_20090629\\_caritas-in-veritate\\_en.html](http://www.vatican.va/holy_father/benedict_xvi/encyclicals/documents/hf_ben-xvi_enc_20090629_caritas-in-veritate_en.html).

Bretzke, James. *A Morally Complex World: Engaging Contemporary Moral Theology*. Collegeville, MN: Liturgical Press, 2004.

Catholic Health Association. "Fast Facts." Accessed November 22, 2012. [http://www.chausa.org/Pages/Newsroom/Fast\\_Facts/](http://www.chausa.org/Pages/Newsroom/Fast_Facts/).

Faust, Halley and Paul Menzel. *Prevention vs. Treatment: What Is the Right Balance?* Oxford: Oxford University Press, 2012.

Hamel, Ron. "Catholic Identity, Ethics Need Focus in New Era." *Health Progress*. 94, no. 3 (May-June 2013):85-87.

Harrelson, Walter J., and Donald Senior. *The New Interpreter's Study Bible*. Nashville: Abingdon Press, 2003.

Kass, Nancy. "An Ethics Framework for Public Health." *American Journal of Public Health*, 2001; 91:1776-1782.

Kenny, Nuala. "Cure vs. Prevention: Catholic Perspectives," In *Prevention vs. Treatment: What's the Right Balance?*, edited by Halley S. Faust and Paul T. Menzel. Oxford: Oxford University Press, 2012.

Mann, Jonathan. "Medicine and Public Health, Ethics and Human Rights." *The Hastings Center Report* 27 no. 3 (1997): 6-13.

Miller, G., Roehrig, C., Hughes-Cromwick, P., and Lake, C. "Quantifying National Spending on Wellness and Prevention," in *Advances in Health Economics and*

- Health Services Research: Beyond Health Insurance, Public Policy to Improve Health.* Emerald Group Publishing Limited, 19 (2008): 1-24.
- Padberg, John. "Catholic Health Care: The Mission and the Ministry," in *Parameters* Vols. 1-4, 1983: 1-8.
- The Pontifical Council for Pastoral Assistance to Health Care Workers. "The Charter for Health Care Workers." Vatican City, 1995. Accessed November 22, 2012. [http://www.vatican.va/roman\\_curia/pontifical\\_councils/hlthwork/documents/rc\\_p\\_c\\_hlthwork\\_doc\\_19950101\\_charter\\_en.html](http://www.vatican.va/roman_curia/pontifical_councils/hlthwork/documents/rc_p_c_hlthwork_doc_19950101_charter_en.html).
- Powers, Madison and Ruth Faden. *Social Justice: The Moral Foundations of Public Health and Health Policy.* Oxford: Oxford University Press, 2006.
- Rosen, George. *A History of Public Health.* Baltimore: The Johns Hopkins University Press, 1993.
- Russell, Louis B. "Prevention vs. Cure: An Economist's Perspective on the Right Balance," In *Prevention vs. Treatment: What's the Right Balance?*, edited by Halley S. Faust and Paul T. Menzel. Oxford: Oxford University Press, 2012.
- Schneider, Mary-Jane. *Introduction to Public Health.* Sudbury, MA: Jones and Bartlett Publishers, 2011.
- UNAIDS. "UNAIDS 2012 Report on the Global AIDS Epidemic." Accessed December 1, 2012 <http://www.unaids.org/en/resources/publications/2012/>.
- United States Catholic Conference. "Health and Health Care: A Pastoral Letter of the American Catholic Bishops." November 19, 1981. Accessed November 22, 2012 <http://old.usccb.org/sdwp/national/HEALTH.PDF>
- United States Conference of Catholic Bishops. "Ethical and Religious Directives for Catholic Health Care Services." November, 2009. Accessed November 22, 2012. <http://www.usccb.org/about/doctrine/ethical-and-religious-directives/>
- World Health Organization. "The Global Burden of Disease: 2004 Update." Geneva: 2004. Accessed November 22, 2012. [http://www.who.int/healthinfo/global\\_burden\\_disease/2004\\_report\\_update/en/index.html](http://www.who.int/healthinfo/global_burden_disease/2004_report_update/en/index.html).

# Hand Feeding: Moral Obligation or Elective Intervention?

Carol Taylor, Ph.D., RN  
Senior Research Scholar  
School of Nursing & Health Studies  
Georgetown University  
Washington, DC  
[taylorcr@georgetown.edu](mailto:taylorcr@georgetown.edu)

Robert Barnet, MD, MA  
Adjunct Professor of Medicine  
School of Nursing & Health Studies  
Georgetown University  
Washington, DC  
[phbobmd@gmail.com](mailto:phbobmd@gmail.com)

“Don’t feed him, please. Bring the tray and set it in front of him. But if he doesn’t eat don’t help him. He would never want to live this way.”

Increasingly those caring for institutionalized individuals with cognitive impairments are being asked not to hand feed residents who are capable of eating safely but whose brains fail to tell them to bring food and drink to their mouths. Behind these requests is usually a loving family member worn down by the relentless ravages of Alzheimer’s disease or another dementia. Surprisingly, professional caregivers lack consensus about whether hand feeding is part of basic nursing care like paying attention to hygiene and helping with toileting or instead, an optional intervention, like ventilatory support, which may be foregone if a valid surrogate requests no hand feeding.

In a recent survey in a large hospice professional caregivers were split almost 50/50 when asked if they would honor a request not to hand feed. Those in favor of honoring these requests generally offer as a rationale, respecting the autonomous preference of a resident as communicated by a valid surrogate using the substituted judgment standard. In some instances an advance directive refusing medical nutrition and hydration in select circumstances was offered as proof that the resident would not want to be hand fed—although the directive did not address hand feeding. Several professional caregivers went so far as to say that they were amending their own advance directives to state that if they were ever in a similar situation they would NOT want to be hand fed. Those opposed to honoring requests not to hand feed were especially troubled when residents seemed to enjoy eating. They believe that if they honor these requests they are definitely causing death by failing to do something they are obligated to do. Further complicating the issue have been recommendations to families who want someone not to be hand fed to take the resident home where they can do as they please. Those who believe that everyone should be hand fed are then in the position of having to decide whether or not to report such a family to adult protective services. At issue is whether or not family caregivers have an obligation to feed these individuals and if failure to do

so is criminal neglect. While this article will address the specific concern about hand feeding, the underlying issue of what care is owed cognitively impaired individuals will serve as a backdrop. One family member recently opined, “Society is soon going to have to decide what to do about all the people we are warehousing.”

### First, a Clarification.

This article is not addressing the decision of whether or not to initiate tube feeding for persons with advanced dementia who can no longer swallow. The overwhelming medical consensus is that long-term tube feeding for individuals with advanced dementia offers no advantages and incurs a number of disadvantages.

The focus of this article is individuals with serious cognitive impairments who can swallow, but who need assistance with oral feedings, or hand feedings. At issue is whether hand feeding can be stopped at the request of a valid surrogate. While there are a few articles addressing voluntarily stopping eating and drinking (VSED) in the bioethics literature, there is very little written about assistance with oral feedings or hand feeding and we could find nothing in the nursing literature about whether or not nurses are obligated to hand feed patients who can eat, and who in many cases, enjoy eating when helped. The first mention of hand feeding in the bioethics literature that we could find occurs in Joanne Lynn’s, *By No Extraordinary Means: The Choice to Forgo Life-Sustaining Food and Water* (1986).

The American Geriatrics Society (AGS) in its “Feeding Tubes in Advanced Dementia Position Statement” (2013) writes:

1. Percutaneous feeding tubes are not recommended for older adults with advanced dementia. Careful hand feeding should be offered; for persons with advanced dementia, hand feeding is at least as good as tube feeding for the outcomes of death, aspiration pneumonia, functional status and patient comfort. Tube feeding is associated with agitation, increased use of physical and chemical restraints, and worsening pressure ulcers.
2. Efforts to enhance oral feeding by altering the environment and creating patient-centered approaches to feeding should be part of usual care for older adults with advanced dementia.

While this is a clear endorsement of hand feeding for this population the statement does not address whether hand feeding is elective. The Alzheimer’s Association statement, however, is adamant in urging that neglect in the area of hand feeding should not be tolerated.

The Association asserts that it is ethically permissible to withhold nutrition and hydration artificially administered by vein or gastric tube when the person with Alzheimer’s disease or dementia is in the end stages of the disease and is no longer able to receive food or water by mouth. The Association

emphasizes that assisted oral feeding should be available to all persons with advanced Alzheimer's disease. **Neglect in this area should not be tolerated, and concerted efforts are called for to educate and support professional and family caregivers in techniques of assisted oral feeding [emphasis added].**

### The Case for Respecting Requests to Not Hand Feed

Cantor (2009) affirms that a surrogate acting on the previously documented wishes of a now-incompetent patient to reject all forms of nutrition and hydration in certain circumstances is appropriately using the substituted judgment standard of decision making to affirm the patient's autonomous choices. Absent prior instructions, the surrogate's decision "would likely be grounded on the conclusion that continued existence in a present highly debilitated state is inconsistent with the patient's best interests (in avoiding intolerable indignity as defined by widespread preferences of people fixing their own medical fates)". Tellingly, Cantor concludes his article noting that a competent patient's right to reject oral nutrition and hydration is revocable given a "change of mind" –a fact that raises many practical questions about a surrogate's permissible course of action:

If an incompetent patient accepts hand feeding, is that a revocation of prior instructions? Can a surrogate decide that in order to

respect the patient's prior considered decision no nutrition and hydration should be offered to the now-incompetent patient? What if a now-incompetent patient spontaneously requests a milkshake or even a drink of water? Can the surrogate—knowing that hydration may prolong the dying process—ignore the requests (relying on the patient's best interests) or even seek sedation as an alternative way to make the dying patient more comfortable? (p. 58).

Dr. Stanley Terman of Caring Advocates is an advocate for what he terms "natural dying." Natural dying, like natural child birth, does not depend on high tech medicine, and it requires even less skilled assistance for nature to take its course. When our brains can neither understand how to eat nor appreciate food, natural dying lets three things occur:

1. Cease manual assistance with oral feeding (as ultimately provided by skilled personnel),
2. Withhold/withdraw all life-sustaining treatment, and
3. Provide the best possible comfort care for a peaceful transition (<http://caringadvocates.org/AD-PND.PO-PND.php>)

Terman's stated mission is to "help competent individuals exercise the option of Voluntary Refusal of Food & Fluid which is legally available everywhere, which is peaceful if thirst is controlled, and which all competent patients can

use.” His particular outreach is to those who fear that they will lose the ability to refuse food and fluid once dementia or a similar disorder deprives them of the ability to reason and communicate.

Terman recommends that individuals who choose to die this way complete copies of his Natural Dying Advance Directive and Natural Dying Physician Order—both of which can be downloaded from his website. He also offers Natural Dying Living Will Cards/My Way Cards which present what it is like to live with advanced dementia. The My Way Cards are for “people who champion the right of self-determination.” The Natural Dying Living Will Cards are for people “who want to follow the teaching of their religion or to be sure that their decisions are moral.”

Terman’s website includes “A Catholic View on the Natural Dying Living Will Cards,” by Kevin McGovern, a priest and Catholic ethicist in Australia. McGovern identifies the sorts of circumstances in which hand/spoon feeding or other treatments will become extraordinary or disproportionate—without conflicting with Catholic teaching.

*The Natural Dying — Living Will* cards therefore allow us to identify what we regard as the ordinary means of preserving life. They also allow us to identify the sorts of circumstances in which some treatments might become extraordinary or disproportionate, and therefore may be refused, withheld or withdrawn. ...

The cards detail various circumstances, which may occur as the dementia progresses. Many of these circumstances bring with them some extra burdens. At the same time, they render the patient more frail, and diminish their physical and moral resources. They also reduce the patient's capacity to strive for the spiritual purpose of life by knowing, loving and serving God, self and neighbor, and even their capacity just to enjoy life. These diminutions arguably reduce the benefits of ongoing, life-preserving treatment. ... The *Natural Dying — Living Will* cards enable patients or their health care proxies to discern **if some treatments** in some circumstances have become an extraordinary or disproportionate means of preserving life (McGovern) [emphasis added].

### Application of Catholic Teaching

McGovern’s analysis appears to rest on first, categorizing hand feeding as a treatment, and then applying the ordinary (obligatory) extraordinary—disproportionately burdensome (morally optional) distinction. This approach seems flawed to us. In the church’s *Declaration on Euthanasia* we see that euthanasia can result from an act or an omission intended to cause death. If hand feeding is not a treatment but rather a necessary act that obligates both family and professional caregivers, even the beneficent motive to free the patient from

a miserable life, thereby respecting intrinsic dignity, is unethical.

Ultimately, the word *Euthanasia* is used in a more particular sense to mean "mercy killing," for the purpose of putting an end to extreme suffering, or having abnormal babies, the mentally ill or the incurably sick from the prolongation, perhaps for many years of a miserable life, which could impose too heavy a burden on their families or on society. It is, therefore, necessary to state clearly in what sense the word is used in the present document. By euthanasia is understood an action or an omission which of itself or by intention causes death, in order that all suffering may in this way be eliminated. Euthanasia's terms of reference, therefore, are to be found in the intention of the will and in the methods used (Sacred Congregation for the Doctrine of the Faith, 1980).

This teaching is echoed in the *Ethical and Religious Directives for Catholic Health Care Services*—both in the Introduction to the section on Care for the Seriously Ill and Dying and in Directive 58.

The Church's teaching authority has addressed the moral issues concerning medically assisted nutrition and hydration. We are guided on this issue by Catholic teaching against euthanasia, which is "an action or an omission which of itself or by intention causes

death, in order that all suffering may in this way be eliminated." While medically assisted nutrition and hydration are not morally obligatory in certain cases, these forms of basic care should in principle be provided to all patients who need them, including patients diagnosed as being in a "persistent vegetative state" (PVS), because even the most severely debilitated and helpless patient retains the full dignity of a human person and must receive ordinary and proportionate care.

58. In principle, there is an obligation to provide patients with food and water, including medically assisted nutrition and hydration for those who cannot take food orally. This obligation extends to patients in chronic and presumably irreversible conditions (e.g., the "persistent vegetative state") who can reasonably be expected to live indefinitely if given such care. Medically assisted nutrition and hydration become morally optional when they cannot reasonably be expected to prolong life or when they would be "excessively burdensome for the patient or [would] cause significant physical discomfort, for example resulting from complications in the use of the means employed." For instance, as a patient draws close to inevitable death from an underlying progressive and fatal condition, certain measures to provide

nutrition and hydration may become excessively burdensome and therefore not obligatory in light of their very limited ability to prolong life or provide comfort.

### The Challenges of Caregiving

The first time we encountered the request from a wife to have the nursing home staff not hand feed her husband because “he wouldn’t want to live like this,” we were haunted by her statement that “society is going to have to decide what to do with all the folks we are warehousing today.” The wife was seen as a caring person by the staff. She was, however, tired and wanting to “move on.” What she raises is an important societal question perhaps best summed up by Leon Kass, in the book, *Taking Care: Ethical Caregiving in our Aging Society*.

When thinking about caregiving, we have concerns about pension insecurity, rising costs of health care, shortages of available caregivers, and the insufficient number of good nursing homes. We have concerns about the potential neglect or abandonment of the elderly, and the possibility of welcoming euthanasia or assisted suicide as ways to “solve the problem” of lingering old age. Many of us face decisions about forgoing careers in order to act as caregivers, or spending less time with young children in order to care for aged parents, or using funds set aside for a daughter’s college tuition in order to pay for

a father’s nursing home. **In short, we worry about whether we can afford to care, whether we will be willing and able to care, and what we must sacrifice in order to care for the elderly.** And many of us in the middle of life, thinking about growing older ourselves, fear the loss of our powers, the deprivations and loneliness that often accompany old age, and the prospect of being a burden on those we love most (The President’s Council on Bioethics, 2005).

On a personal note, we recently had to pay \$100/day (\$200/day on weekends and holidays) to have a geriatric aide help our debilitated uncle eat breakfast and the evening meal. He was in an upscale skilled nursing facility following surgical repair of a hip fracture, and nursing leadership could not guarantee the extra attention and encouragement he needed to take in enough food and fluids to be hydrated and nourished. The experience forced us to reflect on the care being received by thousands of our frail elderly who lack knowledgeable family advocates or the financial resources to receive what should be basic care.

The staggering human and financial costs of caregiving are perhaps best captured in the following statistics. The Alzheimer’s Association reports that over 5 million Americans are now living with Alzheimer’s disease. One in three people aged 85 and older has the disease. In March, 2014, a report published in the medical journal of the American Academy of Neurology

listed Alzheimer's as the third leading cause of death, after heart disease and cancer (James et al, 2014). The personal costs of caring for someone with Alzheimer's disease can be devastating.

- In 2013, 15.5 million family and friends provided 17.7 billion hours of unpaid care to those with Alzheimer's and other dementias – care valued at \$220.2 billion.
- Nearly 60 percent of Alzheimer's and dementia caregivers rate the emotional stress of caregiving as high or very high; more than one-third report symptoms of depression.
- Due to the physical and emotional toll of caregiving, Alzheimer's and dementia caregivers had \$9.3 billion in additional health care costs of their own in 2013 ([www.alz.org](http://www.alz.org)).

According to the Alzheimer's Association the growing Alzheimer's crisis is helping to bankrupt America.

- In 2014, the direct costs to American society of caring for those with Alzheimer's will total an estimated \$214 billion, including \$150 billion in costs to Medicare and Medicaid.
- Nearly one in every five dollars of Medicare spending is spent on people with Alzheimer's and other dementias.
- Average per-person Medicare spending for those with Alzheimer's and other dementias is

three times higher than for those without these conditions.

- Average per-person Medicaid spending for seniors with Alzheimer's and other dementias is 19 times higher than average per-person Medicaid spending for all other seniors.
- Unless something is done, Alzheimer's will cost an estimated \$1.2 trillion (in today's dollars) in 2050. Costs to Medicare and Medicaid will increase nearly 500 percent ([www.alz.org](http://www.alz.org)).

Even if advances are made against the ravages of Alzheimer's and other dementias we face a growing number of frail elderly with increasing limitations, disabilities and dependencies. It was appropriate for Kass to query:

*How we care for the dependent elderly will test whether modern life has not only made things better for us but also made us better human beings, more willing to accept the obligations to care and more able to cope with the burdens of caregiving.* Put simply, can a society that values self-reliance, personal freedom, and careerism reconcile itself to the realities of dependence, diminished autonomy, and responsibility for others? (The President's Council on Bioethics, 2005, p. 4 ).

*Amour* is a 2012 French-language film about the caregiving challenges an elderly couple face when the wife, Anne, suffers a

stroke, which paralyzes her on one side of her body. The film, which won the Palme d'Or award at the 2012 Cannes Film Festival and the Academy Award for Best Foreign Film at the 85<sup>th</sup> Academy Awards, painfully illustrates the difficulties involved as the husband, George, patiently helps to feed, bathe, toilet and move Anne—with very little help from neighbors and their one daughter. The ending for many is tragic. Overwhelmed by Anne's suffering, George picks up a pillow and smothers her. *Amour*, and the recent dismissal of charges against a Philadelphia nurse who allegedly handed her suffering father a bottle of liquid morphine to fulfill his death wish but who said she only handed him the medicine to alleviate his pain, exhort reflection on how we ought to respond to those who present with overwhelming suffering and related challenges for caregivers. Is hastened death the only or best response?

In striking contrast to *Amour* is Leo Tolstoy's short story, *The Death of Ivan Illich*. Tolstoy notes that in the third month of Illich's illness everyone, including Illich himself, was simply waiting for him to die, "to vacate his space. "All were aware that now other people's only interest in him "consisted in the question of how soon he would leave his place empty, free the living from the constraint of his presence, and be free himself from his sufferings" – all except Gerasim, the butler's assistant. As Tolstoy tells the story, Illich was becoming more uncomfortable and Gerasim, a simple young man from the village, was helping Illich with his basic needs. Illich asked Gerasim if caring for him was

disagreeable. Gerasim replied: "Mercy why shouldn't I do it? It is a matter of you being sick." It was not whether what Gerasim did would prevent his dying or would be of "benefit" to Illich, but whether to support him, to meet his basic needs, to hold him was the natural human thing to do.

In my own experience as a young physician, I worked at a Franciscan mission in Zambia. There I met Vincent, a young man brought to the clinic from a distant village. Vincent had leprosy. We built him a house and provided for his basic needs. Soon other lepers joined this community. Not long after my return to the U.S., I learned from Father Joseph Scoma, a Franciscan priest from Italy, that there was concern on the part of some of the Americans and Europeans teaching at schools of the mission about having people with leprosy in the community. Father Joseph had told them: "Vincent is the reason we are here." Two years ago, I returned to the mission for a visit. Vincent had now been there 50 years. The settlement had grown to some 40 lepers. The persons with leprosy lived there with their families. Vincent was close to death and needed assistance with eating. The people in the community fed him and met his needs. He died naturally two weeks after my visit.

One final story. As a third year medical student on my surgical rotation I was assigned to a large ward at Chicago's Cook County Hospital where I was asked to help care for an elderly woman, Mary, with severe decubiti. The medical students were asked to help Mary meet her daily

needs and to provide “wound care.” She changed little during those three months. What we did had little effect on the decubiti. If anything they worsened. I do think, however, that we affirmed her worth and inherent dignity. Mary taught us the meaning and value of our ability to be compassionately present to another and affirmed why many of us had chosen medicine.

When it comes to feeding and meeting other basic human needs, both at the beginning and at the end of life, the normal human response is to meet those needs. This may require the use of a cup, a spoon or even our fingers to provide basic sustenance. It is not something extraordinary, but something simple and ordinary. It is not something that should be medicalized. Families are floundering. What can we offer? Some Catholic nursing homes are training volunteers to assist with hand feedings. Few Catholic parishes are formally engaged in developing programs to assist family caregivers.

### Conclusion

As a just and caring society, we need to explore new ways to meet the basic needs of all the members of our communities. Many aspects of our lives have become institutionalized and medicalized and are becoming more so. We need to seek out alternatives that involve family, friends, neighbors, members of our faith communities, and that are home or community based.

As Gospel communities committed to continuing the healing mission of Jesus, it is always appropriate to ask, “What would Jesus do?” Unfortunately there are no accounts in Scripture of Jesus hand feeding an individual with dementia. There are however, numerous accounts of Jesus reaching out to the outcasts of the day. It seems fitting to conclude with our church’s call to each of us to find the “boundless kindness and charity needed to serve our vulnerable sisters and brothers.”

The norms contained in the Vatican’s present *Declaration on Euthanasia*, are inspired by a profound desire to service people in accordance with the plan of the Creator. Life is a gift of God, and on the other hand death is unavoidable; it is necessary, therefore, that we, without in any way hastening the hour of death, should be able to accept it with full responsibility and dignity. It is true that death marks the end of our earthly existence, but at the same time it opens the door to immortal life. Therefore, all must prepare themselves for this event in the light of human values, and Christians even more so in the light of faith. As for those who work in the medical profession, they ought to neglect no means of making all their skill available to the sick and dying; but they should also remember how much more necessary it is to provide them with the comfort of boundless kindness and heartfelt charity. Such service to people is

also service to Christ the Lord,  
 who said: "As you did it to one of  
 the least of these my brethren, you  
 did it to me" (*Mt. 25:40*)  
 (*Declaration on Euthanasia*, 1980).

**References**

Alzheimer's Association National Board of Directors, "Assisted Oral Feeding and Tube Feeding," (September 2011).  
[http://www.alz.org/documents\\_custom/statements/assisted\\_oral\\_tube\\_feeding.pdf](http://www.alz.org/documents_custom/statements/assisted_oral_tube_feeding.pdf)

American Geriatrics Society (AGS), "Feeding Tubes in Advanced Dementia Position Statement, (May 2013).  
[http://www.americangeriatrics.org/files/documents/feeding\\_tubes.advanced.dementia.pdf](http://www.americangeriatrics.org/files/documents/feeding_tubes.advanced.dementia.pdf)

Cantor, N.L., "The Straight Route to Withholding Hand-Feeding and Hydration," *The American Journal of Bioethics* 9, no.4 (2009): 57-58, DOI: 10.1080/15265160802716829  
 To link to this article:  
<http://dx.doi.org/10.1080/15265160802716829>

Finucane, T.E., Christmas, C., Travis, K., "Tube Feeding in Patients with Advanced Dementia: A Review of the Evidence," *Journal of the American Medical Association* 282, no. 14 (October 13, 1999):1365-1370.

International Association of Catholic Bioethicists. "Statement on Caring and Giving Hope to Persons Living with Progressive Cognitive Impairments and Those Who Care for Them," *The National Catholic Bioethics Quarterly* 10, no. 3 (Autumn 2010): 552-567,  
[http://eprints.nuim.ie/3516/1/ML\\_Statement.pdf](http://eprints.nuim.ie/3516/1/ML_Statement.pdf)

James, B.D., Leurgans, S.E., Heber, L.E., et al., "Contribution of Alzheimer Disease to Mortality in the United States," *Neurology* 82, no. 12 (March 25, 2014). Published online before print March 5, 2014,  
 doi: 10.1212/WNL.0000000000000240  
 Neurology 10.1212/WNL.0000000000000240.

Lynn, Joanne, ed., *By No Extraordinary Means: The Choice to Forgo Life-Sustaining Food and Water*. Bloomington: Indiana University Press, 1986.

McGovern, Kevin, "A Catholic View on the Natural Dying Living Will Cards."  
<http://caringadvocates.org/natural-dying-living-will-cards.php>.

President's Council on Bioethics, *Taking Care: Ethical Caregiving in an Aging Society*. Washington, DC: U.S. Executive Office of the President, 2005. Also available at  
[https://bioethicsarchive.georgetown.edu/pcbe/reports/taking\\_care/taking\\_care.pdf](https://bioethicsarchive.georgetown.edu/pcbe/reports/taking_care/taking_care.pdf).

Sampson EL, Candy B, Jones L, "Enteral Tube Feeding for Older People with Advanced Dementia," *Cochrane Database of Systematic Reviews* 2009, Issue 2. Art. No.: CD007209. DOI: 10.1002/14651858.CD007209. pub2.

Sacred Congregation for the Doctrine of the Faith, *Declaration on Euthanasia*, 1980.  
[http://www.vatican.va/roman\\_curia/congregations/cfaith/documents/rc\\_con\\_cfaith\\_doc\\_19800505\\_euthanasia\\_en.html](http://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_19800505_euthanasia_en.html)

United States Conference of Catholic Bishops, *Ethical and Religious Directives for Catholic Health Care Services*, Washington, DC: USCCB, 5<sup>th</sup> ed., (November 17, 2009).  
<http://www.usccb.org/issues-and-action/human-life-and-dignity/health-care/upload/Ethical-Religious-Directives-Catholic-Health-Care-Services-fifth-edition-2009.pdf>.

## Feeding Decisions

Feeding decisions come in many varieties, and not all are linked to artificially administered nutrition and hydration. Health care professionals committed to health, well-being and good dying need to reflect on the nursing and ethical challenges present in each of the situations below. I have used these scenarios in many professional settings and each time was struck by the diversity of opinions about what qualified as an ethically good response. One of the scenarios is a clear example of suicide by omission as described in the *Declaration on Euthanasia* and another describes the sort of individual in a permanent vegetative state who is the object of the papal allocution on artificial nutrition and hydration and the response by the Congregation for the Doctrine of the Faith.

In the Roman Catholic tradition, the *sensus fidelium* is the "sense of the faithful," one of the valid sources of truth in Catholic theology. This source of truth represents the combined beliefs, consciences and experiences of good and honest Catholics. It operates in a close relationship of mutual conditioning with all of the other varied components of the Roman Catholic tradition. When it comes to feeding decisions Catholic health care professionals are obligated to reflect on the situations in which individuals with altered nutrition and hydration find themselves. In doing so, as committed Christians, they have the opportunity to enrich their insights with the church's magisterial teaching and the best of theological thought.

In my experience, as both a nurse and ethicist, the growing tendency today to abdicate medical decision making to patients and families—even when their expectations are unrealistic and their decisions ill-advised—is simply wrong. The primary object of all clinical decision making ought to be to secure the patient's interests, health, well-being, good dying—and to do this in a manner that respects the integrity of all who participate in the decision making process, patient, family, *and* health care professionals. To the extent this is true, health care professionals must continually reason prudentially about what constitutes good care and make appropriate recommendations to patients, families and their church.

- Mrs. Gleason is a 92-year-old nursing home resident with end-stage dementia. Until now she has been spoon fed. She was admitted to the hospital for recurrent aspiration pneumonia and respiratory difficulties. She has been receiving intravenous fluids. Her altered blood chemistries and frail condition result in her being considered for placement of a PEG feeding tube before being discharged back to the nursing home. She has no family.
- Mr. Suarez is a 49-year-old attorney who was found collapsed at the foot of his stairs at home two weeks ago. He had a massive cerebral head bleed and surgery revealed extensive, irreversible neurologic damage. His medical condition is now stabilized and his doctors are asking his family if they want to "peg and trach him"—in which case he might live for some time with good nursing care. The other option is to transition at this point to primarily palliative goals (not administer medical nutrition and hydration), in which case he will most likely die within 7-21 days. His wife is certain that he would not want to live in his present condition, "he always lived in his mind," but the suddenness of his condition

leaves her wondering if a decision to transition to purely palliative goals isn't premature.

- Jean Bridges is a 24-year-old survivor of an accidental strangling episode. Jean has a long history of schizophrenia. While hospitalized for dehydration, she was found dangling over her bedside with her posey vest restraint around her neck. This was 15 months ago and she has now been diagnosed as being in persistent vegetative state. Her case manager approaches her parents for the first time asking if they had ever considered stopping her medical nutrition and hydration.
- Ms. Apold is an educated, articulate, and until recently, healthy 78-year-old single woman. She does have advanced osteoporosis. A recent fall resulted in a leg fracture. She has lived a rich and full life and sees nothing but diminishment in her future with a life increasingly constricted to her apartment. When she told someone that she wished she could just fall asleep and never wake up, her friend told her that she should just stop eating and drinking—if she really wants to die. Her friend works for hospice. Ms. Apold is now asking this hospice to care for her until she dies.
- Mr. Phan was found dead in his bed at home. Aged 97, Mr. Phan lived alone in an apartment in the city. He had no family of record but friendly neighbors. His closest neighbor described Mr. Phan's multiple health problems, congestive heart failure, chronic obstructive pulmonary disease, diabetes mellitus, peripheral vascular disease and said that she had noticed him really "slowing down" the past year. "I used to bring him food all the time but he just seemed to lose his appetite this year and most of what I brought him was untouched. He wouldn't hear of going to a nursing home. Should something else have been done?"
- Mr. Spivac, aged 80, has the type of dementia which has resulted in his being physically assaultive. He was dismissed from nine residential treatment facilities because the staff's inability to control his behavior. His assaultive behavior is now being managed pharmacologically which has simultaneously impaired his physical functioning. His wife, whom everyone describes as "long-suffering," is now repeatedly asking the doctors and nurses not to help feed her husband. "Bring him a tray but don't encourage him. He never wanted to live like this." He is physically able to feed himself and to swallow but needs encouragement to eat and drink enough to keep him nutritionally balanced. Staff believe that eating is one of his few pleasures at this time. His wife stated that society is going to have to decide what to do with all the people we are now "warehousing" in nursing homes.

# Exploring the Next Frontier: Clinical Ethics for the Physician's Office

Marianne L. Burda, M.D., Ph.D.

Wexford, Pa.

[burdam@consolidated.net](mailto:burdam@consolidated.net)

Clinical ethics activities (education, consultations, policy development, and closing ethics quality gaps) traditionally occur in the hospital and inpatient settings where the sickest patients and the most ethically challenging issues and cases are usually located. But medicine is increasingly emphasizing shifting patient care to the outpatient setting and physician's office whenever possible. According to the Centers for Disease Control 2010 National Ambulatory Care Survey, one billion physician office visits occurred that year.<sup>1</sup> The advent of Accountable Care Organizations, patient centered medical homes, insurance reimbursement based on quality instead of quantity of care, telemedicine, and continued advancements in pharmaceuticals and technologies all contribute to this trend.<sup>2</sup> Even as clinical ethics programs struggle to gain an active and visible presence in some hospital and inpatient settings, they must keep up with the changes occurring in health care and expand to the next frontier—the physician's office. Crucial conversations and decisions about which potentially life-saving treatment and care patients pursue or decline frequently take place in the physician's office. Many day-to-day routine office activities include ethics issues physicians and office staffs may

never think about, for example, conflicts of interest associated with the sale of medications and products to patients. Physician office staffs, especially if located off the main health system campus or employed by a private physician practice, can be somewhat isolated and unaware of where to turn when value conflicts arise. Educational opportunities may be few and far between. Office quality and safety initiatives may not include identifying and closing ethics quality gaps, resulting in missed opportunities to improve the overall quality of care for patients.

This paper outlines a clinical ethics program for the physician's office setting, drawing on office safety and quality initiatives as development sources. The physician's office clinical ethics program consists of three parts: education, implementation, and evaluation, each of which will be discussed in detail. Unique barriers and challenges to implementing physician's office clinical ethics programs include the number of offices, their varying locations and schedules, the diversity of staffs and specialties, and the ownership of physician practices. Utilization of technology, media, and other creative tools to help overcome these challenges and barriers, especially with

providing ethics education, will be described.

The concept of outpatient clinical ethics appeared in the literature in the 1980s, with the focus on ethical issues physicians encounter in the outpatient setting and their ability to recognize and evaluate them.<sup>3</sup> One study found about one-third of internal medicine office patients had ethical problems that influenced their health care.<sup>4</sup> The authors of the study concluded these findings established “a rational basis for the development of curricula and research agendas concerning ethical problems in primary care offices.”<sup>5</sup> In 1989, La Puma and Schiedermayer published “a taxonomy of outpatient clinical ethics problems” based on three categories – problems of dual loyalty, problems of communication, and problems of professional and social responsibility.<sup>6</sup> Felder, almost doubling the size of the list, expanded the taxonomy in 2002. Examples of additional ethics issues on Felder’s list include informed consent, confidentiality, justice considerations, and conflicts in values.<sup>7</sup> The 1989 and 2002 taxonomies include ethics issues found in both the hospital and physician’s office setting.

Outside of an article calling for a code of ethics in the ambulatory care setting in 1995,<sup>8</sup> outpatient ethics was not really addressed in the literature again until 2002 when *The Journal of Clinical Ethics* devoted an entire issue to the subject. In this issue, Potter and Kaiser stated: “Attending to outpatient ethics will clarify, redirect, and energize bioethics... Outpatient ethics is the next

stage of evolution in bioethics, as it has grown from the clinical setting of the hospital, to the organizational level of corporate healthcare, and now out into the human community where everyday existence is lived.”<sup>9</sup>

Quality and safety initiatives evolved from the clinical hospital setting, to healthcare organizational levels, and into the outpatient setting and physicians’ offices, with the goals of improving patient care and processes. Payment from healthcare insurers, in some instances, is based on physician office practices meeting various qualities of care metrics. Safety initiatives, for example, include formal programs by national medical organizations, such as the American Congress of Obstetricians and Gynecologists (ACOG) and the Safety Certification in Outpatient Practice Excellence (SCOPE) program.<sup>10</sup> These initiatives can also cover clinical ethics issues. For example, SCOPE includes informed consent processes, patient rights, and conflicts of interest as part of the physician’s office safety evaluation.<sup>11</sup> But merely incorporating ethics into office quality and safety initiatives is not sufficient. Crucial ethics issues, such as conflicts of values, may be missed relying only on quality and safety programs for a physician’s office’s clinical ethics program. A separate, comprehensive physician’s office clinical ethics program directed at all staff members is required.

But barriers exist to the implementation of a physician’s office clinical ethics program. While integrated health systems can require employee participation in clinical ethics office programs, no regulatory

standard compels private physician practices to initiate this type of program. Unlike quality and safety, accreditation by professional organizations and financial incentives from insurance companies are not currently available to entice healthcare systems and private practice physicians to participate in a physician's office clinical ethics program. Time equals money in the office setting, as the primary source of revenue consists in patient encounters and procedures. Physician practices can have multiple locations, with some at a significant distance from the affiliated health system's main campus and each other. Office staffs have diverse duties, backgrounds, and education levels. Staff members may have limited knowledge of and contact with health system ethics programs, except for required compliance-based activities.

A comprehensive physician's office clinical ethics program should begin with education, focusing on clinical ethics issues found in the office setting and ethics resources available to physicians' offices. Education for all types of physicians' offices can include healthcare ethics principles, theories, values, and issues applicable to all specialties. In addition, education about ethics committees and clinical ethics consultations, how to access the health system's ethics resources, and how to identify and close ethics quality gaps should be taught. Additional educational programs can focus on case-based topics or issues specific to each medical specialty (neurology, psychiatry, etc.) or a certain position in the office (nurse, billing, etc.). Physician's offices may combine

educational activities with other parts of the health system, other offices of the same medical specialty, or in the same physical location.

Creativity will be required in many cases to ease staff members' ability to participate, minimize time away from patient activities, and promote engagement for staff. One such solution is utilizing technology and communication tools. Teleconferencing, webinars, call-in lines, and online education programs can connect staff with clinical ethics experts and education programs in other locations without requiring travel. Simulation of cases and scenarios depicting specific ethics issues using mannequins, standardized patients, and web-based virtual patients can engage and assist staff in learning how to identify and resolve ethics issues. An example of this is a web-based virtual patient case that educates office staff on advance directives and end-of-life planning. Computer access is the only equipment required to participate in this form of education. Staff can do these cases on their own or with other staff members. Media, literature, and art can also be used to actively engage physician's office staff in clinical ethics education. An office or department book club exploring pertinent ethics issues illustrated in different books, for example, is well suited to teleconferencing or call-in formats.

Implementing physician's office clinical ethics programs requires support from the physician's practice itself, the affiliated health system, and on a larger level, professional medical organizations and regulatory/accreditation agencies,

especially to overcome the previously mentioned barriers. One possible implementation strategy involves health systems providing physicians' office clinical ethics programs to both affiliated private physician practices and integrated physician offices, as high quality ethics programs in the office setting will prevent many inpatient ethics issues in the future. Local efforts can include health system ethics personnel reaching out to the office staff, such as visiting office sites and assessing their needs, the ethics issues they encounter, and personally inviting them to participate in a physician's office clinical ethics program. Ethics personnel and office staff can partner with other departments in the health system, such as information technology and education, to link offices and ethicists. Offices can also reach out to local universities or health systems besides their own for access to ethicists and ethics resources, along with exploring the ethics resources provided by local medical societies and national medical organizations. For example, the American Medical Association's and Veterans Health Administration's ethics resources, programs, and publications are available online and at little or no cost.

Hospital ethics committees and consult services can include office staff personnel as members, ensuring ethics issues unique to the physician's office are addressed, along with creating a more inclusive atmosphere to encourage physicians' office staff to bring forth ethics concerns and request consults. Health system ethicists and ethics committees can also assist staff in the development of office ethics policies, such as informed consent,

withholding and withdrawing of treatment, conflicts of interest, etc.

An ethics quality program to close gaps between best ethics practices and current ethics practices in the physician's office can be incorporated into the office's overall quality program. Problems in the health care setting typically have both quality and ethics components. The goal is for staff to recognize that ethics is as important as technical competence and customer service.<sup>12</sup> Office staff may already be improving ethical practices without realizing it or establishing it as the main goal. A large oncology practice in Kansas City, for example, discovered its quality improvement initiatives, such as prevention of errors, evaluation and improvement of pain management and end-of-life care, led to a commitment to ethical practice by the staff.<sup>13</sup>

The visible support of the leadership of each individual physician's office and its affiliated health system are key to the successful implementation of a physician's office clinical ethics program. Leadership should promote and champion the program. Leadership should provide appropriate personnel, finances, and other needed resources required to support and grow the program. The office and health system cultures are also crucial for the program's success, with leadership setting the tone. Leaders at the physician's office and health system levels should foster an organizational environment and culture that makes it easy for all staff to do the right thing.<sup>14</sup> The physician's office culture should not be based on reward and punishment, but should be value-based,

empowering employees to identify, discuss, and resolve ethical issues.<sup>15</sup>

Other methods for obtaining buy-in and participation from physicians and office staff include no charges or fees for the affiliated health system ethicists' time and expertise, educational programs, and technology used to access these programs. Clinical ethicists and ethics activities should accommodate physician's office staff schedules to minimize interference with patient care. Providing continuing educational credits for appropriate staff members also offers incentive for participation. Increasing patients' awareness of the importance of ethics to health care personnel's providing high quality, safe care can also promote physician office participation and propel ethics to the forefront of patient care. Many safety initiatives and programs were initiated by or partner with patients, such as the Josie King Foundation.<sup>16</sup>

Acknowledging participation by physician's offices in a clinical ethics program may also prompt increased buy-in. ACOG's SCOPE program certifies ob/gyn offices that meet the program's standards and criteria, recognizing them on the organization's website and in its academic journal.<sup>17</sup> Although physicians' offices cannot be certified in this same manner from an ethics perspective, acknowledging publicly their participation in a physician office clinical ethics program by providing a certificate of participation to display and listing them in the affiliated health system publications (hospital and community newsletters) and websites, may provide incentive for

individual offices to participate, especially if practices see their competition participating.

Physicians' offices owned by an integrated health system can mandate participation in a clinical ethics program, but this excludes practices that are privately owned. Of course, mandates by accrediting and regulatory agencies would force participation regardless of who owns the physician practice.

Ethics programs should also adopt the saturation-training model used in safety, which holds changes in culture and behaviors may occur when enough learners are educated in a skill in a short period of time.<sup>18</sup> Based on this model, if only one or two staff members participate regularly in a physician's office ethics program and the rest do not, the individuals who participate may not put into practice the clinical ethics knowledge they acquire. However, if all staff members receive clinical ethics education and incorporate clinical ethics knowledge into their daily work, then it becomes the new norm and the new way of doing things for everyone who works in that physician's office. When new individuals join the staff, they will quickly learn that ethical practices and participation in a clinical ethics program are the norm for that physician's office.<sup>19</sup>

Like quality and safety programs, a physician's office clinical ethics program requires ongoing evaluation. Individual physician's offices can designate an individual (manager, physician, etc.) to oversee the program and gather

information for evaluation. This individual can liaison with the health system ethicist; schedule, assign and track completion of ethics education assignments for staff; lead and evaluate the development and implementation of ethics office policies and procedures; and lead and evaluate ethics quality initiatives. Individual physician's office staff members' evaluations can include an ethics component to assess their ethics knowledge and provide information for future clinical ethics program planning. Patient surveys and data collection, similar to that used in other health care quality initiatives, can also identify issues for ethics programs to address and evaluate the impact of the clinical ethics program.

The same as hospital clinical ethics programs, physicians' office clinical ethics programs can provide numerous benefits to staff members, patients, and the health care organization. These include improved patient communication, shared decision-making, patient and staff satisfaction, productivity, quality of care, and safety. A comprehensive clinical ethics program can also safeguard the practice's future. Additional benefits include decreasing unwanted care, utilization of resources, and future value conflicts.<sup>20</sup>

The decades-long shift of health care to the outpatient and physician's office setting rather than the inpatient hospital setting continues, with no reversal of this trend in sight. Therefore, despite the barriers present, clinical ethics must follow patients and health care professionals to the physician's office environment and establish vibrant, comprehensive

physician's office clinical ethics programs as called for in the literature in the 1980s and again in 2002. Likewise, health system and physician's office leadership must partner with clinical ethicists and clinical ethics programs to implement and support these efforts. Only then will health care personnel truly provide all patients with high quality, safe medical care and treatment.

### Notes

<sup>1</sup> CDC, "2010 National Ambulatory Medical Care Survey," accessed at [www.cdc.gov/nchs/ahcd.htm](http://www.cdc.gov/nchs/ahcd.htm), accessed 3/24/2014

<sup>2</sup> Michael Felder, "Outpatient Ethics: 'And the Walls Came Tumbling Down,'" *The Journal of Clinical Ethics*, 13, no. 4 (Winter 2002): 282-283.

<sup>3</sup> Marian Gray Secundy, "Ethical Dilemmas in Office Practice: Physician Response and Rationale," *Journal of the National Medical Association*, 77, no. 12 (1985): 999.

<sup>4</sup> Julia E. Connelly and Steven DalleMura, "Ethical Problems in the Medical Office," *JAMA*, 260, no. 6 (August 12, 1988): 815.

<sup>5</sup> Ibid.

<sup>6</sup> John La Puma and David L. Schiedermayer, "Outpatient Clinical Ethics," *Journal of General Internal Medicine*, 4 (September/October, 1989): 413.

<sup>7</sup> Felder, p. 285.

<sup>8</sup> Isaac D. Montoya and Alan J. Richard, "The Case for a Code of Ethics in an Ambulatory Care Setting," *Journal of Ambulatory Care Management*, 18, no. 3 (1995):68-76.

<sup>9</sup> Robert Lyman Potter and Christy Kaiser, "Bringing Moral Order to the Ordinary: Outpatient Ethics Takes Shape," *The Journal of Clinical Ethics*, 13, no. 4 (Winter 2002): 274.

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- <sup>10</sup>. American Congress of Obstetricians and Gynecologists Safety Certification in Outpatient Practice Excellence for Women's Health, <http://www.scopeforwomenshealth.org>, accessed March 29, 2014.
- <sup>11</sup>. Ibid.
- <sup>12</sup>. Ellen Fox, Bette-Jane Crigger, Melissa Bottrell, and Paul Bauck, IntegratedEthics, "Ethical Leadership: Fostering an Ethical Environment & Culture," *Veterans Health Administration National Center for Ethics in Health Care*, p. 15.
- <sup>13</sup>. John E. Hennessy and Marcus Neubauer, "Quality Improvement and Ethics: Performance Improvement in an Oncology Practice," *The Journal of Clinical Ethics*, 13, no. 4 (Winter 2002): 353-358.
- <sup>14</sup>. Fox et al., Ethical Leadership, pp. 13-14.
- <sup>15</sup>. Ibid, pp. 13-15.
- <sup>16</sup>. Josie King Foundation, [www.josieking.org](http://www.josieking.org), accessed 3/29/2014.
- <sup>17</sup>. ACOG SCOPE.
- <sup>18</sup>. Timothy C. Clapper and Grace M. Ng, "Why Your Team STEPPS Program May Not Be Working," *Clinical Simulation in Nursing*, 9, no. 8 (2013):e288
- <sup>19</sup>. Ibid.
- <sup>20</sup>. IntegratedEthics, "A Brief Business Case for Ethics," [www.ethics.va.gov/businesscase.pdf](http://www.ethics.va.gov/businesscase.pdf), *Veterans Health Administration National Center for Ethics in Health Care*, accessed 3/29/2014

## The CDF Principles

On February 17, 2014, Cardinal Gerhard Mueller, Prefect of the Congregation for the Doctrine of the Faith, responded to a question (a *dubium*) sent to the Congregation on April 15, 2013. The question had to do with whether a Catholic health care system could become a non-Catholic health care system. Cardinal Mueller did not directly respond to the question, stating that it was “framed around a particular set of circumstances to such a degree that it concerns more the application of moral principles to concrete situations and less an articulation or clarification of the operative moral principles.” Instead, the Congregation, in order to assist U.S. bishops in navigating collaborations and structures in Catholic health care, sent a document titled, *Some Principles for the Collaboration with Non-Catholic Entities in the Provision of Healthcare Services*, consisting of 17 principles.

Reaction to the principles has been varied. Some believe they offer nothing really new. Others believe that they go well beyond a traditional articulation of the principles governing cooperation with the wrongdoing of others and could raise challenges for Catholic health care in present and future partnerships. While CHA and the ministry are very interested in the meaning and implications of the principles, CHA is first awaiting clarification of the principles from the bishops.

## Jahi McMath and Brain Death

On December 12, 2013, physicians at Children’s Hospital in Oakland pronounced 13-year-old Jahi McMath brain dead as a result of profuse bleeding post-surgery for addressing her sleep apnea. Brain death was confirmed by several independent neurologic exams, but Jahi’s parents refused to accept that she had died. They went to court to prevent discontinuation of ventilator support. Per a court agreement, Jahi’s body was given to the family and, according to the family’s attorney, ventilator and nutritional support were provided to Jahi in an undisclosed location.

Several articles have since appeared in response to this situation. “Accepting Brain Death” by David Magnus et al appeared in the *New England Journal of Medicine* (370, no. 10 [March 6, 2014]: 891-894) and “Legal and Ethical Responsibilities Following Brain Death: The McMath and Munoz Cases” by Lawrence Gostin appeared in the *Journal of the American Medical Association* (311, no. 9 [March 5, 2014]: 903-904). Both articles describe the case (along with the Munoz case) and review the development of brain death criteria for determining that death has occurred. Both articles make salient observations.

Gostin points out that “once a patient has died, any conversation about the appropriate form of medical treatment is no longer relevant. This would mean, for example, that while Jahi’s mother could ask for ventilation for a short duration to

enable her to come to terms with her daughter's death, the very idea of 'treatment,' especially if it is of an indefinite duration, would be well beyond the bounds of prevailing ethical or legal thought" (904). The family's insistence on continued ventilation and artificial nutrition and hydration, and all that accompanies these, not only would have required physicians to violate their ethical responsibilities by treating a dead person, but also consumed resources that could have been used to provide effective treatment for other patients, according to Gostin. He concludes his short piece by observing that "at one level, the outcome of these cases seems so clear—both individuals have died and they have a right to a dignified burial; and the physician's ethical responsibilities to treat are finished. At another level, the sheer symbolism of a beating heart, together with the human emotions of a loving parent or spouse, suggest that these kinds of cases at the intersection of law, ethics, and medicine will continue" (904).

Magnus et al., after noting some opposition to the concept of brain death, reaffirm its validity. They write:

Given the brain's importance in determining who we are and its crucial role in driving the activity of bodily organs and systems, it is not surprising that loss of cortical and brain-stem function should be equated with death.

Seen in this light, the decision reached by the medical and particularly the neurology

community to articulate and promulgate the concept of brain death as the right place to draw the line between life and death is extremely reasonable. There are clear medical criteria that can be reliably and reproducibly utilized to determine that death has occurred. If professional standards are followed properly, there are no false positives. Brain-dead patients are clearly past the point of any possibility of recovery ... The law and ethics have long recognized that deferring to medical expertise regarding the diagnosis of brain death is the most reasonable way to manage the process of dying. Nothing in these two cases ought to change that stance (894).

A third analysis of the McMath case, "Jahi McMath and Determining Death," appeared in *Ethics and Medics* (39, no. 3 [March 2014]:3-4) and was authored by the ethicists of the National Catholic Bioethics Center. They too support the determination of death by neurological criteria. After quoting John Paul II's "Address to the 18<sup>th</sup> International Congress of the Transplantation Society" (August 29, 2000), they state: "The Catholic Church considers the application of these criteria to be a legitimate means of determining death and has always maintained that it is the competency of the medical profession to declare death" (4). Directive 62 of the *Ethical and Religious Directives* confirms this. At the point of declaration of death, "there would be no moral obligation for a hospital or physician to perform any

procedure on a corpse such as placing a feeding tube or trying to stabilize the bodily functions that are kept working using mechanical means ...” (4).

But as Magnus et al. point out, at one level, this is so clear, but at a human and emotional level what should be done becomes very difficult, and this is not likely to change no matter how clear are the concept of brain death and the criteria by which to determine that it has occurred.

### Ella

Several inquiries have come our way in recent months regarding the use of Ella for emergency contraception. In the next issue of HCEUSA, we will update our review of the literature on the drug’s mechanism of action.

### RH

## Of Note

### Women Still Left Out of Medical Research: Report

Although the number one cause of death in women is cardiovascular disease, women represent less than one-third of the participants in clinical trials. A report released in March at a national summit on women's health issues found that women are underrepresented in studies of non-reproductive conditions. With fewer women participants, there is a lack of information regarding the impact gender has on disease and treatment. Dr. Lynn Gordon, associate dean of diversity affairs at the David Geffen School of Medicine at the University of California, Los Angeles, commented that researchers do not want to do studies on women because of their monthly hormonal changes and possible negative effects on pregnancy and unborn children. But Dr. Gordon adds, these are concerns not excuses. Dr. Paula Johnson, executive director of the Connors Center for Women's Health and report author, calls for an expansion of the existing law which requires women to be included in government-funded medical research. Johnson said, "there are still enormous gaps in the scientific process as it relates to women." Mary Brophy Marcus, *Health Day*, March 3, 2014, <http://consumer.healthday.com/clinical-trials-information-35/clinical-trials-news-136/women-still-being-left-out-of-medical-research-report-685362.html>.

### Study Says New Method Could Be a Quicker Source of Stem Cells

In Kobe, Japan and Boston, Mass., researchers are developing a new technique to grow stem cells. The technique involves taking cells from blood or skin and exposing them to stress for 30 minutes in a mildly acidic solution. The researchers used cells of newborn mice and found white blood cells to be the most efficient. The cells that survived the acid bath became known as STAP cells, standing for stimulus triggered acquisition of pluripotency. Other studies were conducted to show that STAP cells were not abnormal and could turn into any type of cell in the body. The research has been replicated with adult monkey cells and newborn human cells but not with adult human cells. There is interest in understanding why cells revert to a primordial state when exposed to stress. Andrew Pollack, *The New York Times*, Jan. 29, 2014.

### Ethicists Warn Against Three-Parent Reproductive Technology

Robert P. George, McCormick Professor of Jurisprudence at Princeton University, and Dr. Donald Landry, chair of the department of medicine at New York Presbyterian Hospital, composed a letter to the Food and Drug Administration concerning a new reproductive technology that uses the genetic information of three parents. The new technology, oocyte modification in assisted reproduction,

takes DNA from a healthy father and a mother with a mitochondrial DNA defect and inserts it into an egg from a woman with healthy mitochondrial DNA. The letter states that human trials “should not be permitted because of the profound safety, efficacy, policy and social problems they would pose.” Other issues mentioned include deliberate destruction of embryos, unnatural parental relationships, and effects on the development and cognitive behavior of the child. The authors believe this research “would be reckless and immoral.” Catholic News Agency, Feb. 24, 2014, <http://www.catholicnewsagency.com/news/ethicists-warn-against-three-parent-reproductive-technology/>.

### **Paying Kidney Donors Can Save \$\$, Help Patients**

Researchers in Canada have created a decision analysis model to study the effect of paying kidney donors. The model estimated that payment of \$9,648 (\$10,000 Canadian) to kidney donors could increase the number of kidneys available by 5 percent. This would save \$328 (\$340 Canadian) per patient and gain 0.11 quality-adjusted life years. This model did not take into account ethical concerns or the fact that this act is illegal in the U.S. and Canada. Lianne Barnieh, Ph.D., of the University of Calgary and author of the study, stated, “We need more living kidney donors and we need to at least consider paying them ... this research may raise awareness and foster a debate about how we can move forward, respecting the law and ethical

considerations.” An accompanying editorial by Peter P. Reese, MD, and Matthew Allen, BA, of the University of Pennsylvania Perelman School of Medicine, cited ethical arguments against paying donors, including unjust inducement, undue inducement, crowding out and commodification. Salynn Boyles, Oct. 25, 2013, [www.medpagetoday.com/Nephrology/KidneyTransplantation/42483](http://www.medpagetoday.com/Nephrology/KidneyTransplantation/42483).

### **As Drug Trials Fail, Alzheimer’s Researchers Look Toward Prevention**

According to recent studies in the *New England Journal of Medicine*, two beta amyloid inhibitors, once-promising drugs, failed to improve cognition in patients with Alzheimer’s disease. Dr. Jeff Cummings, director of the Cleveland Clinic’s Center for Brain Health, recently said that some risk factors for Alzheimer’s cannot be controlled such as age and genetics, but behavioral, dietary and environmental factors can be altered to decrease the likelihood of the disease. Although research has not given up on the use of beta amyloid inhibitors, a new set of studies is likely to focus on stopping the rapid multiplication of the tau protein which causes cell death in the brain. Dean Hartley, director of science initiatives for the Alzheimer’s Association, stated, “We need a broad portfolio of research that not only looks at plaques and tangles in the brain, but at the multiple risk factors that may impact Alzheimer’s.” Sabriya Rice, *Modern Healthcare*, Jan. 27, 2014.

## Unreported Robot Surgery Injuries Open Questions for F.D.A.

The Food and Drug Administration keeps a database that lists reports of deaths and injuries at hospitals but has no authority to force hospitals to report. A recent review of reports found that many instances of injuries or complications during surgery involving Intuitive's robotic system were either not reported or reported years later. Angela Wonson, an Intuitive spokeswoman, said that the time gap between injury and report is often due to the fact that company is not made aware of the incident until legal claims are made. The F.D.A. received 3,697 adverse reports involving robotic surgery procedures in 2013 through Nov. 3. Some problems with the robotic systems stem from lack of doctor training on the equipment, lack of studies to identify the advantages and disadvantages of the equipment, and the absence of rigorous human trials. Diana Zuckerman, president of the National Research Center for Women & Families in Washington, DC says the F.D.A. reports offer a late warning system, "There is generally at least a 10-year wait once a device is on the market to have any kind of sense whether it is safe or effective, and by then the device may have changed five times." The F.D.A. is developing a four-step plan to improve monitoring of robotic devices. This plan includes registries of devices with automatic reporting of safety events and development of international networks to combine data. Robert Langreth, Bloomberg.com, Dec. 30, 2013.

## Cheap, Reliable Whole-Genome Sequencing? Not So Fast, Say Stanford Researchers

Researchers at Stanford University conducted a study to examine the process of whole-genome sequencing for clinical use. The researchers sequenced the genome of 12 healthy people and manually analyzed genetic variations with a focus on two to six per person. The study found one participant at a higher risk for breast and ovarian cancer. Frederick Dewey, a co-lead of the study, stated that "It's not possible to predict from a study of 12 people how often this type of clinically actionable discovery will occur, but it definitely supports the use of this technology." The question remains, at what cost? The study took 100 hours of labor by three genetic counselors, three clinicians and one medical pathologist which amounts to a cost of \$17,000. Signe Brewster, March 11, 2014, <http://gigaom.com/2014/03/11/cheap-reliable-whole-genome-sequencing-not-so-fast-say-stanford-researchers/>.

*Students from the Center for Health Law Studies at the 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 Michael K. Morton (J.D. anticipated 2014) and Courtney E. Thiele (J.D. anticipated 2014).*

## Judge Overturns Massachusetts Ban on Controversial Painkiller

U.S. District Judge Rya W. Zobel overturned an executive order by Massachusetts Governor Deval Patrick that had banned the controversial painkiller Zohydro ER in the state. Zobel based her decision on the premise that Patrick's executive order preempted federal law by banning a drug that had already been approved by the Food and Drug Administration (FDA). Zobel ruled that Governor Patrick's order "would undermine the FDA's ability to make drugs available to promote and protect the public health...Although the ban may prevent someone from misusing the drug, the ban prevents all in need of its special attributes from receiving the pain relief Zohydro ER offers." Zohydro ER is a very strong painkiller in the opioid family, the first drug of its kind to contain a pure dose of hydrocodone, which is why the drug has received so much criticism, especially from Patrick. The governor criticized the ruling as one that puts the interests of wealthy drug companies over the interests of public health and safety. Patrick stated, "Addiction is a serious enough problem already in Massachusetts without having to deal with another addictive narcotic painkiller sold in a form that isn't tamper proof." On the other hand, supporters of the drug welcome Zohydro ER's strength, claiming that it allows chronic pain sufferers to take the drug for longer periods of time, limiting the effects of liver damage. Interestingly, the FDA approved the drug last year over the objection of an independent advisory

panel, which recommended rejection of Zohydro ER by an 11 to 2 vote. State attorneys general across the nation have also expressed their disapproval of Zohydro ER, claiming that easy access will hinder their efforts in trying to end the country's prescription-drug abuse crisis. Brady Dennis, *Washington Post*, April 15, 2014,

[http://www.washingtonpost.com/national/health-science/massachusetts-cannot-ban-fda-approved-painkiller-judge-rules/2014/04/15/91436946-c4db-11e3-b574-f8748871856a\\_story.html](http://www.washingtonpost.com/national/health-science/massachusetts-cannot-ban-fda-approved-painkiller-judge-rules/2014/04/15/91436946-c4db-11e3-b574-f8748871856a_story.html).

## \$1.2 Billion Judgment Reversed by Arkansas Court

The Supreme Court of Arkansas recently overturned a \$1.2 billion judgment against drug manufacturer Johnson & Johnson, ruling that the state improperly sued the company under a state law that applies to health care facilities, not pharmaceutical companies. The underlying lawsuit was brought against Johnson & Johnson and its subsidiary, Janssen Pharmaceuticals, for the alleged fraudulent marketing of Risperdal, an antipsychotic drug. Specifically, the state had argued that the companies had not properly communicated the risks associated with Risperdal, and also had marketed the drug for various off-label uses. Risperdal and similar antipsychotic drugs have been linked to increased risk of strokes and death in elderly patients, along with seizures, weight gain and diabetes. The state sued under law that allows for such legal action if fraudulent drug practices would have an adverse effect on a

state program, such as Medicaid. The lawsuit accused the companies of deceptive trade practices and Medicaid fraud in marketing of Risperdal, and sought repayment for millions to Arkansas's Medicaid program for unnecessary prescriptions. In their successful appeal, the companies' attorney argued that there was no fraud or improper reimbursements for Medicaid patients who were prescribed the drug. Chuck Bartels, Associated Press/U.S. News, March 20, 2014, <http://www.usnews.com/news/business/articles/2014/03/20/arkansas-court-tosses-12b-judgment-against-j-j>.

### **Replacement for Pap Test Recommended by Feds**

A federal advisory committee for the Food and Drug Administration (F.D.A.) recommended by a 13-0 vote, that a DNA test should be approved for use as a primary screening tool for cervical cancer. The committee touts the DNA test as a possible replacement to the Pap test, a tool that has been the primary screening device for cervical cancer over the past 60 years. While Pap testing involves examining a cervical sample under a microscope, searching for abnormalities, the DNA test, labeled the Roche test, detects the DNA of human papillomavirus, or HPV, which causes almost all cases of cervical cancer. If the committee vote is adopted by the F.D.A., the DNA test would be allowed to be used as the primary screening tool for cervical cancer in women 25 years of age and older. Proponents of the new Roche test call the DNA screening more

objective, rather than the analysis of a Pap test, which may vary doctor to doctor or laboratory to laboratory. Skeptics of the new test are weary of such a quick change in clinical testing if one were to occur. Andrew Pollack, *New York Times*, March 12, 2014, <http://www.nytimes.com/2014/03/13/health/an-fda-panel-recommends-a-possible-replacement-for-the-pap-test.html>.

## Bibliography: Palliative Sedation

*Editor's Note: The following is an updated version of a bibliography published in the Summer 2011 issue of Health Care Ethics USA. It is being included here as a follow-up to the CHA webinar on palliative sedation on April 29, 2014.*

Baumrucker, S.J., Craig, G., Stolick, M., Morris, G.M., Sheldon, J., "Case Study: Sedation for Palliation of Terminal Symptoms (SPTS), and Nutrition and Hydration at End of Life," *American Journal of Hospice and Palliative Care* 22, no. 2 (March-April 2005):153-7.

Berger, J.T., "Rethinking Guidelines for the Use of Palliative Sedation," *Hastings Center Report* 40, no. 3 (May-June 2010):32-8.

Boyle, J., "Medical Ethics and Double Effect: The Case of Terminal Sedation," *Theoretical Medicine and Bioethics* 25, no. 1 (2004):51-60.

Broeckert B., "Palliative Sedation, Physician-Assisted Suicide, and Euthanasia: 'Same, Same but Different?'" *American Journal of Bioethics* 11, no. 6 (June 2011):62-4.

Cassell, E.J., Rich, B.A., "Intractable End-of-Life Suffering and the Ethics of Palliative Sedation," *Pain Medicine* 11, no. 3 (March 2010):435-8.

Cavanaugh, T.A., "Currently Accepted Practices That Are Known to Lead to Death and PAS: Is There an Ethically Relevant Difference?," *Cambridge Quarterly of Healthcare Ethics* 7 (1998):375-81.

Cellarius, V., "Terminal Sedation and the "Imminence Condition"," *Journal of Medical Ethics* 34, no. 2 (Feb. 2008):69-72.

Cellarius, V., Henry, B., "Justifying Different Levels of Palliative Sedation," *Annals of Internal Medicine* 152, no. 5 (March 2, 2010):332; author reply 333

Chater, S. and R.V., Paterson, J., Jarvis, V., "Sedation for Intractable Distress in the Dying – A Survey of Experts," *Palliative Medicine* 12 (July 1998):255-69.

Cherny, Nathan, "Palliative Sedation," *UpToDate* (Feb. 24, 2014): 1-21.

Cherny, N.I., Portenoy, R.K., "Sedation in the Management of Refractory Symptoms: Guidelines for Evaluation and Treatment," *Journal of Palliative Care* 201 (1994):71-79.

Cherny, N.I., Radbruch, L., Board of the European Association for Palliative Care, "European Association for Palliative Care (EAPC) Recommended Framework for the Use of Sedation in Palliative Care," *Palliative Medicine* 23, no. 7 (Oct. 2009):581-93.

## RESOURCES

Claessens, P., Menten, J., Schotsmans, P., Broeckaert, B., "Palliative Sedation: A Review of the Research Literature," *Journal of Pain and Symptom Management* 36, no. 3 (Sept. 2008):310-33.

Claessens, P., Menten, J., Schotsmans, P., Broeckaert, B.; on behalf of the Palsed Consortium, "Palliative Sedation, Not Slow Euthanasia: A Prospective, Longitudinal Study of Sedation in Flemish Palliative Care Units," *Journal of Pain and Symptom Management* (Sept. 9, 2010).

Curlin, F.A., Nwodim, C., Vance, J.L., Chin, M.H., Lantos, J.D., "To Die, To Sleep: U.S. Physicians' Religious and Other Objections to Physician-Assisted Suicide, Terminal Sedation, and Withdrawal of Life Support," *American Journal of Hospice and Palliative Care* 25, no. 2 (April-May 2008):112-20.

Davis, M.P., Ford, P.A., "Palliative Sedation Definition, Practice, Outcomes, and Ethics," *Journal of Palliative Medicine* 8, no. 4 (August 2005):699-701; author reply 702-3.

Deijck van, Rogier et al., "Determinants of the Administration of Continuous Palliative Sedation: A Systematic Review," *Journal of Palliative Medicine* 16, no. 12 (Dec. 2013): 1624-32.

Diamond, E.F., "Terminal Sedation," *Linacre Quarterly* 73, no. 2 (May 2006):172-5.

de Graeff, A., Dean, M., "Palliative Sedation Therapy in the Last Weeks of Life: A Literature Review and Recommendations for Standards," *Journal of Palliative Medicine* 10, no. 1 (Feb. 2007):67-85.

Eberl, J.T., "Aquinas on Euthanasia, Suffering, and Palliative Care," *National Catholic Bioethics Quarterly* 3, no. 2 (Summer 2003):331-54.

Gates, L.K. Jr., "Palliative Treatment of Last Resort and Assisted Suicide," *Annals of Internal Medicine* 133, no. 7 (Oct. 3, 2000):563-4.

Hauser, K., Walsh, D., "Palliative Sedation: Welcome Guidance on a Controversial Issue," *Palliative Medicine* 23, no. 7 (Oct. 2009):577-9.

Have ten, Henk and Jos Welie, "Palliative Sedation Versus Euthanasia: An Ethical Assessment," *Journal of Pain and Symptom Management* 47, no. 1 (Jan. 2014): 123-36.

Henry, B., Dean, M., Cellarius, V., Librach, L., Oneschuk, D., "To 'Sleep Until Death,'" *Hastings Center Report* 41, no. 1 (Jan.-Feb. 2011):4; author reply 4-5.

Jansen, L.A., "Disambiguating Clinical Intentions: The Ethics of Palliative Sedation," *Journal of Medicine and Philosophy* 35, no. 1 (Feb. 2010):19-31.

Jansen, L.A., "Intractable End-of-Life Suffering and the Ethics of Palliative Sedation: A Commentary on Cassell and

- Rich, "Pain Medicine 11, no. 3 (March 2010):440-1; discussion 442.
- Jansen, L.A., "The Moral Irrelevance of Proximity to Death," *Journal of Clinical Ethics* 14, no. 1-2 (Spring-Summer 2003):49-58.
- Kassabian, S., "Palliative Sedation and Physician-Assisted Death," *Journal of Palliative Medicine* 11, no. 6 (July 2008):821.
- Kenny, N.P., Frager, G., "Refractor Symptoms and Terminal Sedation of Children: Ethical Issues and Practical Management," *Journal of Palliative Care* 12 (Autumn 1996):40-5.
- Kirk, T.W., Mahon, M.M.; Palliative Sedation Task Force of the National Hospice and Palliative Care Organization Ethics Committee, "National Hospice and Palliative Care Organization (NHPCO) Position Statement and Commentary on the Use of Palliative Sedation in Imminently Dying Terminally Ill Patients," *Journal of Pain and Symptom Management* 39, no. 5 (May 2010):914-23.
- Koh, Y.H., Lee, O.K., Wu, H.Y., "Palliative" and Not "Terminal" Sedation," *Journal of Pain and Symptom Management* 37, no. 4 (April 2009):e6-8.
- Kon, A., "Palliative Sedation: It's Not a Panacea," *American Journal of Bioethics* 11, no. 6 (June 2011): 41-42.
- Krakauer, E.L., "Responding to Intractable Terminal Suffering," *Annals of Internal Medicine* 133, no. 7 (October 3, 2000):560; author reply 561-2.
- Krizek, T.J., Pellegrino, E.D., Portenoy, R.K., "Palliative Treatment of Last Resort and Assisted Suicide," *Annals of Internal Medicine* 133, no. 7 (Oct. 3, 2000):562-3.
- Lo, B., Rubenfeld, G., "Palliative sedation in dying patients: "we turn to it when everything else hasn't worked,"" *JAMA* 294, no. 14 (Oct. 12, 2005):1810-6.
- Maltoni, Marco et al., "Palliative Sedation in End-of-Life Care," *Current Opinions in Oncology* 25, no. 4 (July 2013): 360-367.
- Materstvedt, L.J., Bosshard, G., "Deep and Continuous Palliative Sedation (Terminal Sedation): Clinical-Ethical and Philosophical Aspects," *Lancet Oncology* 10, no. 6 (June 2009):622-7.
- Morita, T., "Palliative Sedation to Relieve Psycho-Existential Suffering of Terminally Ill Cancer Patients," *Journal of Pain and Symptom Management* 28, no. 5 (Nov. 2004):445-50.
- Muller D., "Re: NHPCO Position Statement on Palliative Sedation," *Journal of Pain and Symptom Management* 40, no. 3 (Sept. 2010):e8-9.
- National Ethics Committee, Veterans Health Administration, "The Ethics of Palliative Sedation as a Therapy of Last Resort," *American Journal of Hospice and*

## RESOURCES

*Palliative Care* 23, no. 6 (Dec. 2006-January 2007):483-91. Review.

Olsen, M.L., Swetz, K.M., Mueller, P.S., "Ethical Decision Making with End-of-Life Care: Palliative Sedation and

Withholding or Withdrawing Life-Sustaining Treatments," *Mayo Clinic Proceedings* 85, no. 10 (Oct. 2010):949-54.

Quill, T.E., Lo, B., Brock, D.W., Meisel, A., "Last-Resort Options for Palliative Sedation," *Annals of Internal Medicine* 151, no. 6 (Sept. 15, 2009):421-4.

Rady, M.Y., Verheijde, J.L., "Continuous Deep Sedation Until Death: Palliation or Physician-Assisted Death?," *American Journal of Hospice and Palliative Care* 27, no. 3 (May 2010):205-14.

Rady, M.Y., Verheijde, J.L., "Sedation for the Imminently Dying: Survey Results from the AAN Ethics Section," *Neurology* 75, no. 19 (Nov. 9, 2010):1753; author reply 1753-4.

Rietjens, J.A., van Delden, J.J., Deliens, L., van der Heide, A., "Re: Palliative Sedation: The Need for a Descriptive Definition," *Journal of Pain and Symptom Management* 37, no. 3 (March 2009).

Rousseau, P., "Existential Suffering and Palliative Sedation: A Brief Commentary with a Proposal for Clinical Guidelines," *American Journal of Hospice and Palliative Care* 18 (May-June 2001):151-3.

Rousseau, P., "Terminal Sedation in the Care of Dying Patients." *Archives of Internal Medicine* 156 (Sept. 9, 1996):1785-86.

Rousseau, P., "The Ethical Validity and Clinical Experience of Palliative Sedation," *Mayo Clinic Proceedings* 75 (Oct. 2000):1064-9.

Russell, J.A., Williams, M.A., Drogan, O., "Sedation for the Imminently Dying: Survey Results from the AAN Ethics Section," *Neurology* 74, no. 16 (April 2010):1303-9.

Sanft, T., Hauser, J., Rosielle, D., Weissman, D., Elsayem, A., Zhukovsky, D.S., Coyle, N., "Physical Pain and Emotional Suffering: The Case for Palliative Sedation," *Journal of Pain* 10, no. 3 (March 2009):238-42. E-pub December 19 2008.

Schildmann, J. and E. Schildmann, "Clinical and Ethical Challenges of Palliative Sedation Therapy. The Need for Clear Guidance and Professional Competencies," *The International Journal of Clinical Practice* 67, no. 11 (Nov. 2013): 1086-88.

Simon, A., Kar, M., Hinz, J., Beck, D., "Attitudes Towards Terminal Sedation: An Empirical Survey Among Experts in the Field of Medical Ethics," *BMC Palliative Care* 6 (April 16, 2007):4.

Stewart, T.L., "To Sleep Before We Die...: When is Palliative Sedation an Option for the Dying Person?," *Journal of Palliative*

*Medicine* 11, no. 1 (Jan.-Feb. 2008):131-2.

Sulmasy, D.P., Curlin, F., Brungardt, G.S., Cavanaugh, T., “Justifying Different Levels of Palliative Sedation,” *Annals of Internal Medicine* 152, no. 5 (March 2, 2010):332-3; author reply 333.

Sulmasy, D.P., Ury, W.A., Ahronheim, J.C., Siegler, M., Kass, L., Lantos, J., Burt, R.A., Foley, K., Payne, R., Gomez, C.,

Sulmasy, D.P., Ury, W.A., Ahronheim, J.C., Siegler, M., Kass, L., Lantos, J., Burt, R.A., Foley, K., Payne, R., Gomez, C., Krizek, T.J., Pellegrino, E.D., Portenoy, R.K., “Publication of Papers of Assisted Suicide and Terminal Sedation,” *Annals of Internal Medicine* 133 (Oct. 2000):564-6.

Sulmasy, D.P., Ury, W.A., Ahronheim, J.C., Siegler, M., Kass, L., Lantos, J., Burt, R.A., Foley, K., Payne, R., Gomez, C., Krizek, T.J., Pellegrino, E.D., Portenoy, R.K., “Responding to Intractable Terminal Suffering,” *Annals of Internal Medicine* 133, no. 7 (Oct. 3, 2000):560-2; disc 561-2.

Swart, S.J., Brinkkemper, T., Rietjens, J.A., Blankaert, M.H., van Zuylen, L., Ribbe, M., Zuurmond, W.W., van der Heide, A., Perez, R.S., “Physicians' and Nurses' Experiences with Continuous Palliative Sedation in the Netherlands,” *Archives of Internal Medicine* 170, no. 14 (July 26, 2010):1271-4.

Sykes, N., Thorns, A., “Sedative Use in the Last Week of Life and the

Implications for End-of-Life Decision Making,” *Archives of Internal Medicine* 163, no. 3 (Feb. 10, 2003):341-4.

Truog, R., et. al., “Barbiturates in the Care of the Terminally Ill,” *New England Journal of Medicine* 327 (Dec. 3, 1992):1678-82.

van der Hoven, B., de Groot, Y.J., Thijsse, W.J., Kompanje, E.J., “What To Do When a Competent ICU Patient Does Not Want to Live Anymore But Is Dependent on Life-Sustaining Treatment? Experience from the Netherlands,” *Intensive Care Medicine* 36, no. 12 (Dec. 2010):2145-8.

Visser, K.C., Hasselaar, J.G., “Palliative Sedation: Need for Consensus Guidelines and Standards: Comment on ‘Continuous Deep Sedation until Death in Belgium: A Nationwide Survey,’” *Archives of Internal Medicine* 170, no. 5 (March 8, 2010):494-5.

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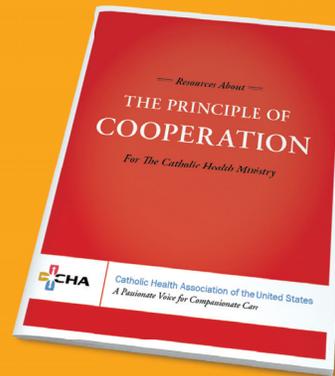
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