

# Health Care Ethics USA

A resource for the Catholic health ministry

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# Early Pregnancy Complications and the ERDs

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## Introduction

The last few months of 2013 and the very beginning of 2014 have seen several attacks on Catholic health care, more specifically, how Catholic health care addresses obstetrical complications. At the annual meeting of the American Society for Bioethics and Humanities in October 2013, Professor Lori Freedman from the University of California, San Francisco delivered a short paper that took Catholic health care to task. She subsequently published an article (together with Debra Stulberg, MD of the University of Chicago) in the October-December 2013 issue of the *American Journal of Bioethics* titled “Conflicts in Care of Obstetric Complications in Catholic Hospitals.”<sup>1</sup>

On Dec. 2, 2013, *The New York Times* published an article, “Bishops Sued over Anti-Abortion Policies at Catholic Hospitals.”<sup>2</sup> The article reports the American Civil Liberties Union (ACLU) lawsuit against the United States Conference of Catholic Bishops (USCCB), claiming that the *Ethical and Religious Directives for Catholic Health Care Services* (ERDs) issued by the USCCB were responsible for “negligent care” of a pregnant woman with an

obstetric emergency being treated in a Michigan Catholic hospital. The article was followed on Dec. 8, 2013 by an editorial, signed by the entire editorial board, titled “When Bishops Direct Medical Care.”<sup>3</sup>

On Dec. 12, 2013, *The Washington Post* published an article, “Catholic Hospitals Are Growing. What Will That Mean for Reproductive Health?”<sup>4</sup> The *Washington Post* article also cites an article by Deborah Stulberg, MD and three other colleagues that appeared in the July 2012 issue of the *American Journal of Obstetrics and Gynecology*—“Obstetrician-Gynecologists, Religious Institutions, and Conflicts Regarding Patient-Care Policies.”<sup>5</sup> Stulberg’s article follows upon another (“Religious Hospitals and Primary Care Physicians: Conflicts over Policies for Patient Care”) published in 2010 in the *Journal of General Internal Medicine*.<sup>6</sup>

A month before the *Washington Post* article, a Colorado newspaper reported that the ACLU had filed a complaint against Mercy Regional Medical Center in Durango, Colo. claiming that the hospital forbids physicians and other employees from discussing abortion with

patients, even if a pregnancy threatens a woman's life.<sup>7</sup> On Dec. 18, 2013, the ACLU together with MergerWatch released a report titled, "Miscarriage of Medicine: The Growth of Catholic Hospitals and the Threat to Reproductive Health Care."<sup>8</sup> Needless to say, newspapers, magazines and blogs across the country picked up this story as well as that of the ACLU lawsuit against the USCCB. Finally, on Jan. 1, 2014, the *New Republic* published an article by Prof. Freedman—"Bishops Run Catholic Hospitals—And Should Be Liable When Their Edicts Lead to Error: New Research into Medical Decisions at Church-Run Facilities."<sup>9</sup>

Freeman and Stulberg, along with the ACLU and MergerWatch, seem to have embarked on a vigorous campaign against Catholic health care in general and the practice of obstetrics and gynecology in Catholic hospitals in particular. Theirs, of course, are not the first such attacks. They are simply the most recent wave. Much could be written about the errors in their work, questionable methodologies, unfounded generalizations, biased selection of events, facts, and interpretations, as well as a general lack of understanding of Catholic health care and of what actually occurs in the vast majority of Catholic hospitals across the country. That, however, is not the purpose of this article.

What follows has a different purpose. It examines four areas relating to obstetrical complications in the hope of providing some greater clarity about the guidance provided by the *ERDs* and the Catholic

moral tradition. The situations that these and other authors describe are rarely the result of the *ERDs* themselves, though these tragic events have been attributed precisely to observance of the Directives. In some instances, there may have been a lack of knowledge about what specific Directives actually say, or a misunderstanding or misapplication of the certain Directives. But this is not the fault of those Directives that are relevant to early pregnancy complications. In other instances, the Directives simply made and make an easy target. The cause of these situations, assuming they occurred as described, may have had nothing to do with the Directives or with the hospital's being Catholic. The four areas to be considered are informed consent, ectopic pregnancy, miscarriage, and preterm premature rupture of membranes (PPROM). These are the primary issues that repeatedly surface in challenges to Catholic health care's dealing with obstetric complications.

### Grounding Convictions and Principles

A Catholic approach to obstetric complications is shaped by several fundamental beliefs and ethical principles. The first of these is respect for the dignity of all human beings. This entails seeking the well-being and flourishing of all, including nascent human life, and doing nothing that would violate the inherent value of all human life. In this regard, the Directives state that "[T]he Church's commitment to human dignity inspires an abiding concern for the sanctity of human life from its very beginning" and that the "Catholic health ministry witnesses to the

sanctity of life ‘from the moment of conception until death.’ The Church’s defense of life encompasses the unborn and the care of women and their children during and after pregnancy.”<sup>10</sup> An immediate consequence of this fundamental conviction is that in cases of obstetrical complications, Catholic hospitals will attempt to save both lives when that is possible. In the vast majority of cases, this is exactly what the mother/parents want. They want to try to save the pregnancy, to have this child, and they want to do whatever is feasible to try to make that happen.

A second consequence of this grounding belief is the moral principle that prohibits the directly intended ending of a pregnancy before viability or the directly intended destruction of a viable fetus. Either would constitute a direct abortion. Directive 45 addresses this. But this is not the last word. Some procedures do not directly intend the termination of a pregnancy and do not have as their sole immediate effect the ending of a pregnancy. Such procedures are considered to be indirect abortions and can be morally permissible. They are justified on the basis of the principle of double effect, another of the ethical principles that shapes how obstetric complications are handled in a Catholic facility.

Briefly, the principle of double effect applies when an action has at least two simultaneous effects—one good and intended and the other bad and foreseen but not intended. The principle has four conditions, all of which must be present

for an action to be considered “indirect” and, thus, morally acceptable. The first is that the act in question (or the procedure) must be “good” or “neutral” in its moral quality. Second, what is intended is the good effect and not the bad. Third, the good and bad effects must occur simultaneously, thus avoiding a situation where the bad effect becomes a means for achieving the good effect. Morally speaking, in the Catholic tradition and elsewhere, one ought not use a bad means to achieve a good end. Finally, there ought to be a proportionate reason, that is, there ought to be a sufficiently serious reason to permit the bad effect. This principle gives rise to several Directives that provide guidance when dealing with particular obstetrical complications, as will be seen below. First, however, we turn to an issue that is not an obstetrical complication, but that is foundational to all decision-making—informed consent.

### **Informed Consent**

One of the charges made against both the Muskegon and Durango hospitals is that the patients involved were not adequately informed about their condition and their choices. This failure is laid at the feet of the Directives. What do the Directives say about informed consent? Directive 26 states that “the free and informed consent of the person or the person’s surrogate is required for medical treatments and procedures . . .” Directive 27 is somewhat more specific. It reads: “Free and informed consent requires that the person or the person’s surrogate receive all reasonable information about the essential nature of the proposed treatment and its

benefits; its risks, side-effects, consequences, and cost; and any reasonable and morally legitimate alternatives, including no treatment at all.” And, finally, Directive 28 states that “each person or the person’s surrogate should have access to medical and moral information and counseling so as to be able to form his or her conscience. The free and informed health care decision of the person or the person’s surrogate is to be followed so long as it does not contradict Catholic principles.”<sup>11</sup> What is to be made of what is said here?

First, it is important to keep in mind the distinction between a direct termination of pregnancy which is morally prohibited, and an indirect termination of pregnancy which is morally permissible when there is a sufficient reason. There should be no question about informing a woman of the possibility of a termination of her pregnancy that is *indirect* in those situations in which it is medically indicated or is a medically feasible option. Quite probably, indirect abortions would cover the vast majority of early pregnancy complications where a termination of pregnancy seems to be medically indicated to resolve the complication. However, what about a direct abortion? Can that be mentioned as part of the informed consent process? While some will disagree, full disclosure of *medically* appropriate or indicated options, *factually relevant information*, including direct abortion, in difficult obstetrical situations can and should occur, within certain parameters. What is the rationale for this and what are the parameters?

It is no mistake that Directives 26-28 come under Part Three of the ERD, which reflects on the nature of the patient-professional relationship. The individual Directives within Part Three discuss critical features of this relationship and outline some of the basic rights and responsibilities of patients and professionals alike. It is also no mistake that the Introduction to Part Three as well as Directive 23 reaffirm the notion of respect for human dignity which is seen as the foundation of the professional-patient relationship. Informed consent is an expression of respect for human dignity. To violate informed consent is to violate human dignity. Intimately related to human dignity and to informed consent is conscience as underscored in Directive 28.

Human beings ought to make decisions that are true to their consciences, to what they discern in their heart of hearts that God is calling them to be and do in the concrete. This is a difficult task that is made all the more difficult when they are not given complete information by those they trust to provide it. A basic moral responsibility of providers in Catholic health care organizations is to communicate *factually relevant information* to patients so they can properly inform their conscience. Directive 28, as already noted, describes this well: “Each person or the person's surrogate should have access to medical and moral information and counseling so as to be able to form his or her conscience.” Receiving such factually relevant information, of course, is only one piece in the formation of an individual’s conscience. Much more is required.

Directive 28 is important for several reasons. First, it recognizes the primacy of conscience by stating that the patient should be given *medical* and moral information necessary to inform her or his conscience. In so doing, the Directive suggests that providers in Catholic health care facilities cannot usurp the moral authority of a patient to direct her or his own life according to her or his conscience by failing to disclose factually relevant information. Second, the Directive implicitly makes a crucial moral distinction between disclosing information and providing services that are not in keeping with Church teaching. It does this by indicating that providers in Catholic health care facilities need not honor all patient decisions, especially those that violate Catholic principles, but they must share factually relevant information with a patient so that she or he can inform her or his conscience. This moral distinction is indispensable if providers in Catholic health care facilities are going to fulfill their medical, moral, and legal responsibilities to patients, while at the same time preserve their identity and professional integrity in a morally pluralistic society as well as the faith-based identity of the organization. Thirdly, Directive 28 speaks to *moral* information. This is another essential component of the formation of conscience and ought not be overlooked in the clinical context. In fact, as will be seen below, disclosure of factually relevant information also provides an opportunity for providing the patient with moral considerations.

It is in the Introduction to Part Three that we find another compelling reason,

beyond that of informing conscience, why providers in Catholic hospitals have a moral responsibility to disclose fully all factually relevant information to the patient. In a word, that reason is *trust*. One of the building blocks of the patient-professional relationship, trust is essential if the patient is going to feel free to share personal information necessary for effective care as well as heed the expert advice of the professional when it comes to following the care plan. If physicians in Catholic hospitals were to routinely and systematically refrain from disclosing factually relevant information, to what extent would that weaken the trust patients have in them and the health care professionals that practice in Catholic facilities? This is not a rhetorical question. It is one that must be taken seriously. The ability of physicians to carry out their healing mission would be gravely undermined if the building block of trust were weakened or destroyed altogether. Of course, there are other reasons for full disclosure of factually relevant information—legal requirements associated with informed consent, avoidance of malpractice lawsuits and, above all, avoidance of serious harm to the pregnant woman.

Earlier, full disclosure of factually relevant information was qualified by “within certain parameters.” What are those parameters? While there are important moral reasons for providing patients with all factually relevant information, the *way* in which the information is imparted is a critical component of the disclosure process. When it comes to actually stating the prohibited option, providers in

Catholic health care organizations should do so in an objective, factual manner, neither approving nor recommending, pointing out that the procedure is not offered in the Catholic facility and explaining *why* this is the case. This is critical for full disclosure to be acceptable morally. It is critical for the patient's own moral education and the formation of his or her conscience, as well as for the integrity of the institution and the professional integrity of the provider. A number of Catholic health care facilities with obstetric departments, especially those that deal with high acuity patients, have a template of script to assist physicians or other clinicians in this communication.

### Ectopic Pregnancy

As is generally well-known, an ectopic pregnancy involves the attachment of an embryo to something other than the endometrium, usually the wall of the fallopian tube. The resulting abnormal growth can result in rupture of the tube, severe hemorrhaging and even death for the mother. In developed countries, the death rate from ectopic pregnancies is approximately 9 to 13 percent, while in undeveloped countries, it is considerably higher. Treatment of ectopic pregnancy can take three forms—expectant management, surgical, and medical.

The first, *expectant management*, consists in simply monitoring the situation to see if the tubal pregnancy resolves on its own. Most women are not candidates for expectant management. *Surgical treatment* can take two forms. One consists in the

partial or complete removal of the fallopian tube, which also contains an embryo (salpingectomy). The other involves slitting the fallopian tube and “stopping the destructive activity of the trophoblast by removing the invasive trophoblastic cells along with the damaged tubal tissue.”<sup>12</sup> The embryo is also necessarily removed in the process (salpingostomy). The third form of treatment, *medical*, consists in the administration of the drug methotrexate which prevents the trophoblastic cells from continuing to divide and doing damage to the tube that could result in severe hemorrhaging. The embryo also eventually dies. The use of methotrexate increasingly seems to be the preferred treatment because it does not involve surgery and leaves the woman's fertility intact. Salpingostomy can also preserve the woman's fertility.

What do the ERDs say about ectopic pregnancies? Directive 48 speaks to this situation: “In case of extrauterine pregnancy, no intervention is morally licit which constitutes a direct abortion.” In light of Directive 48, the question is whether any of the procedures mentioned above constitutes a direct abortion. While the first approach results in the death of the embryo, the embryo's demise is not intended, nor is there any direct attack on the embryo. A pathological tube is removed that results in two effects—prevention of harm to the mother (the intended effect) and the demise of the embryo (the unintended effect). There is clearly a proportionate reason—the mother's well-being is preserved and the embryo, though it dies, actually has no

chance at survival. Virtually all theologians agree that salpingectomy constitutes an indirect abortion and so is morally licit. The demise of the embryo is foreseen, but not intended.

Among Catholic theologians and ethicists, there is disagreement regarding the third and fourth procedures. Some see them as a direct attack on the embryo and, so, a direct abortion,<sup>13</sup> while others see them as aimed at removing pathological tissue—the trophoblast—which unavoidably results in the death of the embryo. They judge this to be an indirect abortion.<sup>14</sup> For example, Ashley, deBlois and O'Rourke state: “[M]ethotrexate is often used to treat the pathology caused by the abnormal location of the fertilized ovum. While it would be wrong to detach a fertilized ovum from its normal site of implantation, to detach it from an abnormal site that constitutes a serious pathological condition in the woman’s body would seem to be licit. Hence, the direct intrinsic intention ... of the surgical or pharmaceutical act ... seems to be to protect the health of the mother, and the death of the conceptus is not intended. For this reason, it is our opinion that salpingostomy and the use of methotrexate do not result in direct abortion and therefore are in accord with Directive 48.”<sup>15</sup> *The magisterium has not resolved this controversy.* Hence, neither Church teaching nor the ERDs forbid the third or fourth approaches (so long as these approaches can legitimately be argued as not constituting direct abortions). Currently, both opinions are in play.

If some Catholic hospitals have policies that prohibit salpingostomy and the use of methotrexate, this is not because these procedures are forbidden by Church teaching or by the ERDs. Rather, it is because an individual or individuals decided either to take the safer course or personally believed that salpingostomy and/or the use of methotrexate constitute direct abortions and are, therefore, in conflict with Directives 48 and 45. However, given the ongoing debate, it is permissible for Catholic hospitals to employ both salpingostomy and methotrexate. As the editors of the National Catholic Bioethics Center’s *Catholic Health Care Ethics: A Manual for Practitioners* note: “Resolution of the debate will depend on further specification of the exact nature of these medical procedures and further refinement of the arguments about the moral object of each act. Generally, if there are two competing but contrary bodies of theological opinion about a moral issue, each held by experts whose work is in accordance with the magisterium of the Church, and if there is no specific magisterial teaching on the issue that would resolve the matter, then the decision makers may licitly act on either opinion until such time that the magisterium has resolved the question.”<sup>16</sup>

### Miscarriage

Another of the obstetric complications that the ERDs supposedly prevent from being adequately treated is miscarriage of which there are several types. A *missed miscarriage* occurs when there is a fetal demise (usually for a number of weeks),



but there is no uterine activity to expel the products of conception. A *complete miscarriage* occurs when all the products of conception have been expelled without the need for surgical or medical intervention. A *threatened miscarriage* occurs when any bleeding is seen during pregnancy prior to 20 weeks' gestation. Upon examination, it may be found that the fetus remains viable and the pregnancy continues without any further problems. Expectant management (i.e. bed rest) is the typical treatment. When there is vaginal bleeding with dilation of the cervix and the fetus has not yet been expelled an *inevitable miscarriage* exists. In these cases, bleeding can be severe and abdominal pain and cramping often occurs. This situation virtually always progresses to a complete miscarriage. There may or may not be a fetal heartbeat. An *incomplete miscarriage* occurs when there has been expulsion of some but not all of the products of conception before the 20<sup>th</sup> week of pregnancy. Parts of the fetus, placenta, or membranes might have been retained. Vaginal bleeding is heavier and abdominal pain is almost always present. The mouth of the womb is open and the pregnancy is being expelled. Some miscarriages can become septic, a *septic miscarriage*. Here, tissue from a missed or incomplete miscarriage becomes infected. This condition carries the risk of spreading (septicemia) and poses a grave risk to the life of the mother.<sup>17</sup>

The treatment options for miscarriage are three—expectant management or watchful waiting, surgical evacuation of the products of conception, and medical (chemical) evacuation. While surgical

intervention has been the conventional treatment for first trimester pregnancy loss and is the treatment of choice for unstable patients, non-surgical treatments have been increasingly introduced and appear to be effective and satisfactory for certain patients.<sup>18</sup> With expectant management or watchful waiting 65-80 percent of miscarriages resolve within 2-6 weeks with no higher a complication rate than from a surgical intervention. Nor is there any difference in short term psychological outcomes. Medical management involves the use generally of misoprostol to prompt the completion of the miscarriage. It has been shown to be as effective as manual vacuum aspiration with complete evacuation rates of 95-99 percent after 1-2 weeks. Surgical treatment (dilation and curettage or vacuum aspiration) is the fastest way to complete the miscarriage. It shortens the duration and heaviness of bleeding and avoids the pain associated with miscarriage, but has its own complications. Some studies suggest that there is no indication for routine surgical management. Medically, surgical treatment is indicated when the woman has unstable vital signs, uncontrolled bleeding, or evidence of infection. Selection of treatment obviously depends on the clinical situation and the patient's judgment.

How might we think about these treatments from an ethical perspective? Two Directives are relevant here. Directive 45 states: "Abortion (that is, the directly intended termination of pregnancy before viability or the directly intended destruction of a viable fetus) is never permitted. Every procedure whose

sole immediate effect is the termination of pregnancy before viability is an abortion.” And, the second, Directive 47 states: “Operations, treatments, and medications that have as their direct purpose the cure of a proportionately serious pathological condition of a pregnant woman are permitted when they cannot be safely postponed until the unborn child is viable, even if they will result in the death of the unborn child.” Several things need to be noted and kept in mind regarding Directive 47. The *direct purpose* of the intervention is to save the life of the mother or protect her health and not to terminate the life of the fetus. Second, the woman must have a *proportionately serious pathological condition* and the intervention is a treatment/cure for that. Third, the intervention should be a *last resort* (i.e., waiting is not feasible and lesser means have not been or will not be effective). Fourth, the Directive recognizes that the intervention might *result in the death of the fetus*, hence, in some cases, the presence of fetal heart tones does not preclude an intervention.<sup>19</sup>

In light of the guidance provided by these Directives, which of the treatment options would seem to be morally acceptable for the various types of miscarriage? Obviously, in cases of a *complete miscarriage*, there is no question of treatment. In a *threatened miscarriage*, expectant management is the morally acceptable treatment because the fetus remains alive and the pregnancy may continue on to term. Medical/chemical and surgical treatment would not seem to meet the requirements of Directive 47 or the conditions necessary for an indirect

abortion. When an *inevitable miscarriage* is at issue, expectant management and medical therapy would both be morally acceptable. If expectant management is not feasible due to excessive bleeding and/or pain or other factors such as the clinical ability of the facility, the use of a pharmaceutical agent to induce labor is not a direct attack on the fetus, but rather a measure to evacuate the uterus in order to resolve a pathological condition. This would be considered an indirect abortion from a Catholic perspective. Surgical management in this situation is more ambiguous. On the one hand, it would seem to be a direct attack on the fetus. On the other hand, surgical management is aimed at evacuating all the products of conception from the uterus of which the fetus is one. In this sense, could it be considered indirect? In the case of an *incomplete miscarriage*, because the fetus is already dead, any of the forms of treatment would be morally permissible. The primary concern here should be the well-being of the mother. The same would be true of a *septic miscarriage*. Of course, whenever the fetus is already deceased, the method of evacuation of the uterus can be determined solely on medical considerations and the judgment of the mother. Any of the methods would be morally permissible.

### PPROM (Preterm Premature Rupture of Membranes)

Preterm premature rupture of membranes, that is, either the complete breakage of the amniotic sac or leakage of amniotic fluid before 37 weeks of gestation (i.e., before

labor and before the fetus has reached maturity), occurs in about 2-3 percent of all pregnancies. The condition poses a potentially grave risk to the fetus which is likely to be delivered within one week of membrane rupture and face complications of prematurity and even death (preterm delivery). It also poses a serious risk to the mother (and fetus) who may develop chorioamnionitis—an infection of placental tissues which can lead to the death of both the mother and fetus within a very short time. “The main risk to mother and fetus in PPRM is the development of infection within the uterus, since the amniotic sac no longer serves as a barrier against infection. The burden on the mother and the fetus is the risk of infection, but depending on how early in pregnancy the rupture occurs, the risk of prematurity may be more significant for the fetus.”<sup>20</sup>

Treatment for PPRM includes hospitalization, expectant management, monitoring for signs of infection, administration of antibiotics and possibly tocolytics to stop preterm labor, and induction of labor to resolve chorioamnionitis should that occur. Determination of appropriate treatment depends to a considerable degree on when PPRM occurs in the pregnancy (the earlier in the pregnancy, the less chance there is for fetal survival and the higher incidence there tends to be for infection), the clinical condition of the mother as well as her socio-economic reality. Later in the early part of the pregnancy, conservative management may reduce the risks of prematurity for the fetus, keeping in mind that the vast majority of women

proceed to active labor and delivery soon after PPRM. Few remain pregnant more than 3-4 weeks after.

Ethically, if infection develops, Directive 47 provides guidance. Labor and delivery may be induced. This would constitute an indirect abortion because it fulfills the conditions of the principle of double effect. As explained by Peter Cataldo and T. Murphy Goodwin: “If evidence of intrauterine infection develops, however, progressive, severe infection of the mother and the fetus can be expected within hours, a life-threatening situation for both. In this setting, induction of labor for maternal benefit is commonly recommended in practice, even though the fetus cannot be expected to survive.”<sup>21</sup> But can induction of labor before twenty-three weeks’ gestation ever be ethically justified, they go on to ask? After noting that in Catholic moral teaching and tradition, induction of labor is evaluated by the principle of double effect, they explain: “In the case of PPRM with evidence of infection in the uterus, the intention of the physician inducing labor is to cure the infection by removing the infected placenta and membranes of the gestational sac. The good effects of curing the mother of ...PPROM are not caused by the death of the baby (third condition). ...[T]he removal of the offending organ, the placenta and membranes, allows survival of the mother, which would otherwise be in doubt (fourth condition).”<sup>22</sup> Finally, they go on to say that there is ample published evidence that when there is no clinical or laboratory evidence of infection, “expectant management and use of antibiotics is an

acceptable course that can result in fetal survival and acceptable maternal morbidity.”<sup>23</sup>

Sr. Jean deBlois and Fr. Kevin O’Rourke, in discussing the Directives in Part Four of the ERDs, offer the following advice in understanding and applying these Directives, especially those discussed here: “[A]ppropriate interpretation and application of the *Directives* also require adequate medical data and an understanding of the pathophysiology of the conditions involved. ... For example, in seeking to observe the norms set forth in Directives 47, 48, and 53, one must know the physical condition of the person in question. It is important to note here that Directive 47 (treating a serious pathological condition of a pregnant woman) and 48 (treating an extrauterine pregnancy) do not seek to impose conclusions divorced from clinical data. Rather, they set parameters within which clinical data must be presented, analyzed, and acted on.”<sup>24</sup>

In making decisions about a course of action in these crisis situations, there are multiple variables to consider including the medical condition of the mother, the age of gestation of the fetus, accepted standards of care for dealing with these situations, the level of clinical care that is available, the patient’s living and family situation, and the woman’s physical, emotional and psychological capacities, among others. These are so often highly complex and too often very tragic decisions. Of utmost importance, is doing what can be done for the well-being of both the fetus and the mother and

discerning that in light of the guidance provided by the Directives.

## Conclusion

While some decisions about how to address complications early on in a pregnancy are relatively straightforward, others are highly complex both medically and ethically. This is due in part to the numerous variables at play, rapidly changing situations, the need so often for relatively quick decisions, and the fact that Catholic health care is committed to the well-being of both the mother and the fetus whose interests sometimes conflict.<sup>25</sup>

Given this reality, the wisdom of deBlois and O’Rourke should be taken to heart by those who have a responsibility for assisting in these decisions. They conclude their discussion of Part Four of the Directives with the following advice: “Appropriate ... respect for unborn human life requires much more than mere adherence to the prescriptions and proscriptions expressed in Part Four. Although specific directives set the parameters for determining appropriate action on behalf of human good, they do not exempt decision makers from reasoned analysis and conscientious decision making.” And they go on to say: “The nature of the materials addressed in Part Four should lead ethics committees [and, I might add, others who provide ethical guidance] in Catholic health care to educate themselves and ensure they understand the issues. Moreover, ethics committees should carry out ongoing educational activities to promote better understanding of the issues and help shape

organizational policy and practice in ways that promote the goods and values in question.”<sup>26</sup>

<sup>1</sup> Lori R. Freedman and Debra Stulberg, “Conflicts in Care for Obstetric Complications in Catholic Hospitals,” *AJOB Primary Research* 4, no. 4 (2013): 1-10.

<sup>2</sup> Erik Eckholm, “Bishops Sued over Anti-Abortion Policies at Catholic Hospitals,” *The New York Times*, December 2, 2013, accessed at <http://www.nytimes.com/2013/12/03/us/lawsuit-challenges-anti-abortion-policies-at-catholic-hospitals.html?ref=unitedstatesconferenceofcatholicbishops>.

<sup>3</sup> The Editorial Board, “When Bishops Direct Medical Care,” *The New York Times*, December 8, 2013, accessed at <http://www.nytimes.com/2013/12/03/us/lawsuit-challenges-anti-abortion-policies-at-catholic-hospitals.html?ref=unitedstatesconferenceofcatholicbishops&pagewanted=print>.

<sup>4</sup> Sarah Kliff, “Catholic Hospitals Are Growing. What Will that Mean for Reproductive Health?,” *The Washington Post* (December 12, 2013) accessed at <http://www.washingtonpost.com/blogs/wonkblog/wp/2013/12/02/catholic-hospitals-are-growing-what-will-that-mean-for-reproductive-health/>.

<sup>5</sup> Debra B. Stulberg, Annie M. Dude, Irma Dahlquist, and Farr Curlin, “Obstetrician-Gynecologists, Religious Institutions, and Conflicts Regarding Patient-Care Policies,” *American Journal of Obstetrics and Gynecology* 207 (July 2012) 73e1-5.

<sup>6</sup> Debra Stulberg, Ryan Lawrence, Jason Shattuck and Farr Curlin, “Religious Hospitals and Primary Care Physicians: Conflicts over Policies for Patient Care,” *Journal of General Internal Medicine* 25, no. 7 (2010): 725-30.

<sup>7</sup> Joel Hanel and Shane Benjamin, “ACLU: Mercy Anti-Abortion Policy Illegal,” *Durango Herald* (November 13, 2013), accessed at <http://www.durangoherald.com/apps/pbcs.dll/article?AID=/20131113/NEWS01/131119849/ACLU:-Mercy-anti-abortion-policy-illegal&template=printpicart>.

<sup>8</sup> ACLU and MergerWatch, “Miscarriage of Medicine: The Growth of Catholic Hospitals and

the Threat to Reproductive Health Care,” December 2013, accessed at <https://www.aclu.org/files/assets/growth-of-catholic-hospitals-2013.pdf>.

<sup>9</sup> Lori Freedman, “Bishops Run Catholic Hospitals—And Should Be Liable When Their Edicts Lead to Error: New Research into Medical Decisions at Church-Run Facilities,” *The New Republic* (January 1, 2014), accessed at <http://www.newrepublic.com/article/116034/catholic-hospitals-lawsuit-usccb-doctrines-determine-care>.

<sup>10</sup> United States Conference of Catholic Bishops, *Ethical and Religious Directives for Catholic Health Care Services*, Washington, DC: USCCB, fifth edition, 2009, Part Four, Introduction.

<sup>11</sup> *Ibid.*, Part Four, Directives 26, 27 and 28.

<sup>12</sup> Albert S. Moraczewski, OP, “Ectopic Pregnancy: B. Arguments in Favor of Salpingostomy and Methotrexate,” in Edward J. Furton et. al., eds., *Catholic Health Care Ethics: A Manual for Practitioners*, Philadelphia, PA: The National Catholic Bioethics Center, 2009, p. 122.

<sup>13</sup> See, for example, William E. May, “Ectopic pregnancy: A. Arguments against Salpingostomy and methotrexate,” in Edward J. Furton, et. al., eds., *Catholic Health Care Ethics: A Manual for Practitioners*, Philadelphia, PA: The National Catholic Bioethics Center, 2009, pp. 119-12; Edward Furton, “The Direct Killing of the Innocent,” *Ethics and Medics* 35, no. 10 (October 2010): 1-2..

<sup>14</sup> In addition to the article by Moraczewski cited above, see Peter Cataldo, “Ectopic Pregnancy,” in *New Catholic Encyclopedia Supplement 2009*, Rev. Bernard Marthaler, O.F.M., Conv., ed., Washington, D.C.: The Catholic University of America, 1009, pp. 284-286; Germaine Grisez, *The Way of the Lord Jesus*, vol. 2, *Living A Christian Life* (Quincy, IL: Franciscan Press, 1993), pp. 499-503; Kevin O’Rourke, “Applying the Directives: The Ethical and Religious Directives Concerning Three Medical Situations Require Some Elucidation,” *Health Progress* 79, no. 4 (July-August 1998): 64-66; Martin Rhonheimer, *Vital Conflicts in Medical Ethics: A Virtue Approach to Craniotomy and Tubal Pregnancies*, edited by William F. Murphy, Washington, D.C.: Catholic

University of America Press, 2009, especially pp. 83-121.

<sup>15</sup> Benedict Ashley, Jean deBlois, and Kevin O'Rourke, *Health Care Ethics: A Catholic Theological Analysis*, Washington, D.C.: Georgetown University Press, fifth edition, 2006, p. 82.

<sup>16</sup> Furton, et al., eds., *Catholic Health Care Ethics*, p. 123.

<sup>17</sup> Craig Gabriel, M.D. et al., "Management of Spontaneous Abortion," *American Family Physician* 72 (2005): 1243-50.

<sup>18</sup> Ibid. See also Quynh Bui, "Management Options for Early Incomplete Miscarriage," *American Family Physician* 83 (February 1, 2011): 258-60; I.Casikar, et al., "Expectant Management of Spontaneous First-Trimester Miscarriage: Prospective Validation for the '2-week rule,'" *Ultrasound Obstetrics and Gynecology* 35 (2010): 223-227; B.A. Chen and M.D. Creinin, "Contemporary Management of Early Pregnancy Failure," *Clinics in Obstetrics and Gynecology* 50 (March 2007): 67-88; G. Condous, E. Okaro and T. Bourne, "The Conservative Management of Early Pregnancy Complications: A Review of the Literature," *Ultrasound Obstetrics and Gynecology* 22 (2003): 42-30; M.M. El-Sayed, S.A. Mohamed and M. H. Jones, "Expectant Management of First-Trimester Miscarriage," *Journal of Obstetrics and Gynecology* 29, no. 8 (November 2009):681-5; M. Wieringa-de Waard, et. al., "Patient Preferences for Expectant Management vs. Surgical Evacuation in First-Trimester Uncomplicated Miscarriage," *Journal of Clinical Epidemiology* 57 (February 2004): 167-73.

<sup>19</sup> I am indebted to Michael Panicola, Ph.D., Senior Vice-President, Mission, Legal & Government Affairs, SSM Health Care, Saint Louis for these distinctions.

<sup>20</sup> Peter J. Cataldo and T. Murphy Goodwin, M.D., "Early Induction of labor," in *Catholic Health Care Ethics: A Manual for Practitioners*, ed. by Edward Furton, Peter Cataldo and Albert Moraczewski, O.P., Philadelphia: The National Catholic Bioethics Center, second edition, 2009, p. 112.

<sup>21</sup> Ibid., p. 113.

<sup>22</sup> Ibid.

<sup>23</sup> Ibid., pp. 112-113. See also, Sr. Jean deBlois, CSJ, PhD and Fr. Kevin O'Rourke, OP, JCD, "Care for the Beginning of Life," *Health Progress* 76, no. 7 (September-October 1995): 36-39, 40; reprinted in *Ethical and Religious Directives for Catholic Health Care Services: Seeking Understanding—A Collection of Selected Readings*, Saint Louis: The Catholic Health Association, 2003, pp. 27-32. The reprint is quoted here.

<sup>24</sup> deBlois and O'Rourke, p. 28.

<sup>25</sup> Cataldo and Goodwin, p. 111.

<sup>26</sup> deBlois and O'Rourke, p. 31.

# Moral Distress: A Different Perspective

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Over the past three decades, a literature has emerged identifying, defining, and addressing the phenomenon of moral distress in health care professionals. Since the concept was originated in 1984, many writers have discussed moral distress as a nursing ethics issue, or more broadly as a clinical ethics issue, but there has not been literature addressing moral distress in health care professionals as an organizational ethics issue. In this paper, I will begin the process of doing precisely that.

First, I will discuss the nature of moral distress and why it ought to be considered an organizational ethics issue. Second, I will review several ways health care organizations currently address moral distress and why they are ethically insufficient. Third, I will propose a different way to think about moral distress that is based on the moral equality and moral acquaintanceship of health care professionals. And, finally, I will offer a few practical recommendations for ways health care organizations can address moral distress.

There is no one hard and firm, standardized definition of moral distress in the literature of the health care professions.<sup>1</sup> However, for the purposes of this paper, I will define moral distress as a

situation in which “you believe you know the ethically appropriate action to take, but you are unable to act upon it” and, therefore, “you act or refrain from acting in a manner contrary to your personal and professional values, which undermines your integrity and authenticity.”<sup>2</sup> This occurs most frequently for reasons related to accepted organizational structure, social roles, and power dynamics. Also important to keep in mind is that, as contemporary medical care is most often team care, moral distress can occur when the medical team, or the authoritative party in charge of the team (say, the attending physician) acts in a way that one of its members believes to be ethically inappropriate, and that person does not have the power to effectively raise objections to the decision.

Though the literature on moral distress grew out of, and continues to primarily focus on, moral distress in nursing, I choose to look at the phenomenon across the health care professions, given that the empirical data show moral distress affects “nurses, pharmacists, social workers, physicians, health care managers,”<sup>3</sup> psychologists<sup>4</sup> and psychiatrists.<sup>5</sup> In other words, moral distress occurs in all corners of the health care professions and wherever caregivers provide professional care together. Consequently, it is necessary

to broaden the study of moral distress beyond nursing.

There is no doubt that moral distress is an important clinical issue in health care, but I want to argue that it should also be seen as an organizational ethics issue. The effects of moral distress on health care professionals are diverse and damaging, affecting not only the individual with symptoms like “depression, nightmares, headaches and feelings of worthlessness,”<sup>6</sup> but also the institution. “Moral distress has implications for satisfaction, recruitment and retention of health care providers and implications for the delivery of safe and competent quality care.”<sup>7</sup> Ultimately, unmitigated moral distress leads to professional burnout and, at times, departure from the profession altogether. In addition, given that contemporary medical care is necessarily team care, moral distress can cause rifts in team cohesiveness, especially when the distress situations arise due to differences in ethical judgments among team members. These effects are a direct affront to the mission undertaken by health care organizations, in that it conflicts with the two main priorities of such organizations: the health of the patient, and professional expertise as the basis of decisions in clinical matters.<sup>8</sup>

### **What is Currently Being Done by Health Care Organizations**

Though I believe that they are ethically insufficient, some proposals for reducing or alleviating moral distress among health care professionals can be found in the literature, and even some examples of

actual hospital policy. For example, we could interpret unilateral DNAR orders to be a hospital’s attempt to provide institutional backing for the decision of a medical team to not act in a potentially morally distressing way by attempting resuscitation on a medically untenable patient. Another proposed institutional response comes from Judith Daar,<sup>9</sup> which she calls a “treatment evaluation board”, or TEB. The TEB would be used as a forum in which physicians could: 1) discuss their disagreements over the course of treatment requested by patients, 2) determine how to meet the needs of the patient, and 3) decide how to transfer the patient to another physician or hospital, as needed.<sup>10</sup> While I agree that at least the first two tasks that Daar assigns to her TEB are potentially useful steps for resolving moral distress (though I will explain later why they are not ideal), Daar’s proposal includes a recommendation for how the TEB is to be composed. This recommendation is troublesome. Daar states, “Ideally, a TEB should be composed of two members from the full-time medical staff, one member who represents the hospital administration (this member should serve as the chair of the board), and one member who is a hospital social worker.”<sup>11</sup> Note, however, that *not* included on this board is the health care professional that is experiencing the moral distress—not even as an ad hoc invitee. Instead, the situation is handled hierarchically—it is handed up to hospital administration to be dealt with via the TEB. This seems to be the wrong approach to resolving moral distress. It takes away the voice of, and the proper



share of the decision making from, the morally distressed person.

### Equality in Moral Distress

I would like to propose an alternative approach. In order to deal properly with moral distress, procedures that emphasize and support the moral equality of health care professionals are essential and ought to replace hierarchically based responses. I believe that no one health care provider is more of an expert on the individual experience of moral distress than another, and this means that all health care professionals are to be viewed as equally qualified to contribute to the resolution of morally distressing situations. Moreover, the experience of moral distress carries equal ethical weight for whomever it affects, and for this reason also any response to such distress must recognize all parties involved as moral peers, as opposed to subordinates negotiating with superiors on the organizational chart. In other words, there is something seriously wrong with an organizational solution to moral distress if a superior is tasked with solving a subordinate's personal experience of moral distress.

The experience of moral distress is a personal, individual, and, in important ways, a unique experience – even when several people are distressed at the same set of events. Taking participation in the resolution of a morally distressing situation away from those experiencing the distress marginalizes their experience of the situation in a way that is not ethically appropriate, given that the morally distressed person is feeling the

distress in a potentially unique way. Organizationally speaking, one's superior (or a TEB or a hospital policy) can neither fully understand nor completely fix one's experience of moral distress without one's being engaged as a full and equal collaborator in addressing it. Furthermore, even if only one health care professional is experiencing distress in a given situation, it is in the nature of moral inquiry and reflection that it is accessible to all the health care professionals involved and all are capable of moral reasoning and therefore of contributing as moral equals to the discussion. In addition, given that differing ethical judgments among team members may be the catalyst for moral distress within the team, all those team members involved in the case are causally or contextually related to the moral distress experience, and thus have a contribution to make to discussing it and should participate in its resolution.

I am arguing, therefore, that all health care professionals have the ability to discuss moral distress experiences as equals with important contributions to make toward resolution of distress situations. To support this, it is necessary to understand the kind of moral framework in which such a discussion and resolution by the group of moral equals can occur. Thus, in addition to moral equality, I also want to suggest that health care professionals already have a moral framework within which to express themselves as moral equals in their efforts to address situations of moral distress.

Among health care professionals there is, I maintain, a mutually agreed-upon (to

some extent explicitly, but also to a great degree tacitly) “common moral framework” within which health care professionals routinely operate.<sup>12</sup> This is a “thin” moral framework because it admits of many kinds of variation of moral views and standards from profession to profession, institution to institution, and person to person. But this thin common moral framework is “thick enough” to do two things. First, it delineates what we mean when we discuss “reasonable” experiences of moral distress that an ethically serious health care organization would want to resolve, even when the experience itself is, as shown above, variable and subjective in an important sense. Second, because this much of a moral framework is common to all health care professionals, it can provide the means for creating a peer-to-peer non-hierarchical forum in which to discuss morally distressing situations. By this, I mean that because the assumption is that all health care professionals are in basic (though at times, *very* loose) agreement about what is meant by ethical practice – due, for example, to similarities in training and professionally assumed moral commitments – then in any discussion of a moral distress situation it is reasonable to accept as a starting point that each participant is equipped with a health care professional’s moral compass that is, very broadly speaking, the same as everyone else’s in the conversation.

My defense of the validity of this notion will rest on what I will call a “professional common morality.” The starting point from which I will build my discussion of this framework is Tom Beauchamp’s and

James Childress’ notion of “common morality”, though they use the phrase more broadly than I do.<sup>13</sup> As the authors state, “All persons who are serious about living a moral life already grasp the core dimensions of morality. They know not to lie, not to steal property, to keep promises, to respect the rights of others, not to kill or cause harm to innocent persons, and the like... Because we are already convinced about such matters, the literature of ethics does not debate them. Such debate would be a waste of time.”<sup>14</sup> I think there is something intuitively correct in what they say, although it is a tougher sell to then justify the claim that this common morality gives us four principles from which to begin medical ethical deliberation. The point is, however, that at the very least broad agreement exists amongst “morally serious” people regarding some paradigm issues.

Turning back to professions specifically, by the very nature of what it means to be a professional (as opposed to, say, a member of a trade), those who become professionals are obligated to be “morally serious” about their profession. This means that upon entering a profession, the newly-minted professional is expected to take up certain moral obligations, a commitment often sworn symbolically by oath. Though these professional moral obligations may be vaguely articulated or blandly stated in standard codes, they are understood to be, and expected to be, substantive when practiced. This much common understanding about professional commitments is characteristic of the professions in general. When we focus more narrowly on the health care

professions, I argue that the moral obligations undertaken by health care professionals provide even more of a common moral framework – though still a thin one rather than anything more than that – which identifies patterns of acceptable health care practice or behavior; and it is because of this common moral framework that calling a stressful situation an instance of **moral** distress makes sense in the first place. Thus, we cannot justifiably exclude a particular health care professional from the discussion or resolution of a moral distress situation by claiming he or she doesn't have the ethical background to be involved in it. For all health professionals have this basic grounding in what I am calling a “thin” but genuine “common moral framework.”

It should be noted that I am not claiming that all health care professionals share the exact same set of ethical commitments. For example, bioethics literature traditionally states that doctors have healing as a primary obligation (with different specialties even having differing notions of what that means), while nurses have caring as their primary obligation. However, if we focus on a notion of a “thin” degree of mutual understanding, then I claim that all health care professionals are committed to a set of overlapping convictions that include the aforementioned healing and caring, among other various moral concepts that are a part of the common moral framework. A person from one health care profession could be understood by a person from another health care profession when using these concepts,

even if their rank order differs from profession to profession. Other obligations, then, that might be offered for this shared moral framework might include such things as respect for autonomous decision-making, biological health, avoidance of harm, equitable use of resources, promotion of patient well-being, compassion, empathy, and knowledge of and expertise in one's specialty. Clearly, this is not an exhaustive list, but it stands to reason that any one of the above obligations could be understood in a “thin” sense by all health care professionals.

### Supporting This Equality-Based Approach

In order to explain this idea of a “thin” but genuine common moral framework for health care professionals, I want to summarize two different strains of philosophical thought that support it. The first builds on a proposal found initially in H. Tristram Engelhardt, Jr.'s, *The Foundations of Bioethics*,<sup>15</sup> and further developed by Kevin Wm. Wildes. The second, which I draw from Jürgen Habermas' theory of discourse ethics will lead us to a description of the kind of forum in which what I will be calling “moral acquaintances” can work together to address their moral distress.

Engelhardt's project in *The Foundations of Bioethics* is to find a viable health care ethic given his declaration that there is not, and cannot be, a content-full common morality in this world because of its multitude of ethical viewpoints and lack of a universally agreed-upon moral

authority. There is simply not enough moral agreement, he holds, for us who inhabit this world to be “moral friends” who share common ethical commitments or moral authorities. Instead, he says, we are necessarily “moral strangers” who lack those commitments and authoritative ethical judges.

Obviously, there is an important difference between Engelhardt’s concern for a lack of a content-full morality and my belief that health care professionals are committed to a common moral framework included in their professional obligations. For this shared framework precludes them from continuing to be moral strangers with one another in Engelhardt’s sense, as the common moral framework alluded to above ensures that there is an overlapping conception of ethical practice (though perhaps a thin one) among them as health care professionals. Health care professionals do not start from a “moral square one”, as it were, and thus we need not be stuck with a *content-less* procedural morality. Certainly, though, it does not follow that health care professionals must be moral friends, as not all moral content can (or necessarily should) be shared by all health care professionals. Here, Kevin Wm. Wildes’ theory of moral acquaintanceship,<sup>16</sup> can be helpful because it provides a fuller conceptual basis for describing the kind of forum that is needed for health care professionals to resolve instances of moral distress.

Wildes seeks to find middle ground between the distaste of moral relativism that comes with accepting radical

pluralism as a fact, and the lack of moral choice that comes with enforcing a single ethical system on all people. Believing that Engelhardt’s polarized labels of moral friends and moral strangers are not sufficiently comprehensive, Wildes introduces the term “moral acquaintances” to fill in the gap. “Moral acquaintances” exist when “the parties involved understand another’s moral world and share it in part.”<sup>17</sup> Wildes believes it is this vision of acquaintanceship that is most often at work in secular bioethics. It is why there is often consensus when it comes to basic ethical principles about health care and why even wildly divergent viewpoints can be discussed in a common bioethical language. Thus, Wildes argues, while “moral friends may agree strongly on content; moral strangers may be satisfied with procedural agreements; and moral acquaintances may develop limited, overlapping, substantive, and procedural agreements.”<sup>18</sup>

Given Wildes’ description of these categories, I believe that health care professionals ought to be considered moral acquaintances. Like Wildes, I maintain that moral acquaintances share *part* of each other’s ethical world, namely, the common professional moral obligations I have discussed. Even if these shared obligations are broad and thin, health care professionals understand that their colleagues have also, by the very nature of professionalism, adopted these same professional obligations. They will often understand the obligations a little differently, and might have differing moral backgrounds or personal ethics. But

they also know that important parts of their moral worlds are intertwined because they are health care professionals together. As moral acquaintances, they have enough overlapping training and language that, even when shared answers to ethical questions have not been identified, the participants in the discussion at the very least ought to have understood each other within the framework professionalism creates. They can couch their explanations in terms of adherence to obligations and in a language that is shared, though not necessarily in terms of conformity to a deep moral foundation.

### A Practical Organizational Proposal

I turn now to some insights from Jürgen Habermas' discourse ethics that can contribute to some practical solutions. Some of the theoretical underpinnings of Habermas' work can, in light of the groundwork I have laid out, act as signposts for a practical solution to moral distress in a health care organization. This is due to the fact there are some important parallels between Habermas' discourse ethics and Wildes' moral acquaintanceship.

First, Habermas insists that all affected parties in a moral conflict have an equal chance to hear and be heard; the equality of health care professionals in moral distress situations demands this as well. Second, for Habermas, true consensus is reached through real dialogue among affected subjects; this avoids the problems presented by a hierarchical response to moral distress (including the distressed party being denied a say in the resolution

process, or the inability to have a constructive, real dialogue regarding the situation before it is taken over by an organizational entity removed from the conflict at hand, which makes the discussion theoretical rather than practical). Third, Habermas does not ask for a deep moral bond between parties; he seems to realize that understanding the other's moral world and sharing a part of it is enough to negotiate a consensus under the rules of discourse ethics.

In this way, Habermas provides what could be useful guidelines for addressing situations of moral distress. A resolution would be considered reached when all affected parties are included in the discussion, and though individual interests will have to be modified to be harmonious with other individuals' interests, the process itself would be judged as fair, and the outcome judged as one mutually agreed-upon by all parties as being, minimally, an *acceptable* solution. This is because all parties will have heard and been heard, and, ideally, understand and be understood, even if agreement on every aspect of the relevant moral question is out of reach.

Given the above, I propose, in no particular order of importance, several avenues that a health care organization might pursue in order to address moral distress. First, the organization might pursue a moral distress intervention process in which the focus is on procedural facilitation. Second, the organization could establish a body focused on uncovering the systemic causes of moral distress and providing

educational opportunities to health care professionals. Finally, the organization should work toward the creation of an ethical workplace climate with an emphasis on a non-hierarchical moral culture.

Given the inadequacy of a hierarchical response to moral distress, the equality of health care professionals who all share a thin common morality, and the Habermasian forum in which moral acquaintances can meet and engage in dialogue, it seems clear that neither a clinical ethicist nor an ethics committee ought to be granted power to arbitrate resolutions to moral distress. Rather, the ethicist(s) called to the moral distress situation ought to be charged with bringing about the circumstances in which the participants are treated as equals, given a chance to speak openly and have the opportunity to both understand, and be understood by, all other parties in their articulation of their distress. My own recommendation would be for the organization to employ a full-time ethicist that is known to have autonomy from the organization itself, perhaps analogous to how a newspaper ombudsman is employed by, but editorially separate from, his or her employer. I also advocate against an ad-hoc committee whose independence from the institution may be less clear. I believe that an autonomous ethicist acting as facilitator for discussion would most likely alleviate fears of the organization's sending a committee to "fix" the problem, which in turn removes the worry of a possibly hierarchical response (especially if the cause of moral distress is institutionally-based).

Another recommendation is that health care organizations set up a standing body to study the situations that cause moral distress in order to better understand them, and provide educational opportunities on how to respond to them (or eliminate them when possible). Root-cause analyses of morally distressing situations, as explained by Rushton, could be a way to achieve this that would fall under the purview of the appointed body. Such a body could, as Rushton explains, "use a systems analysis...to explore the systems that have contributed to moral distress. Root cause analysis is a process for identifying what, how, and why an event happened in order to prevent its reoccurrence. Using a neutral process, [the analytic body would] identify interpersonal factors, interdisciplinary dynamics, policies, or practices within the system. This type of process can lead to documentation of institutional constraints that lead to moral distress and identify workable solutions."<sup>19</sup> This body could compile the ethicist notes/reports of moral distress consultations in order to perform such an analysis, and then create educational programs for health care professionals on how to resolve cases of moral distress. Ideally, this would be empowering to health care professionals, as opposed to reinforcing hierarchies—the organization would have to take great care to ensure that health care professionals understand that moral distress resolution can be achieved without "going up the ladder," while still being the source of education.

Of course, it is not a stretch of the imagination to picture an attending

physician or someone else with decision making authority within the institution being uninterested in moral distress education, or refusing to join in moral distress discussions, whether due to perceived time, autonomy, authority, or patterns of practice constraints. The question is how to bring such individuals on board with these institutional changes.

A third recommendation, then, is the creation of an ethical climate in the health care organization. Also known in the business ethics literature as “moral culture,” the goal here would be to create a workplace in which any morally distressed individual would feel—and be correct in feeling—that her concerns were valued and addressed by an organization that is legitimately focused on creating a non-threatening, equality-based atmosphere in order for its employees to be able to morally thrive. Given the above discussion, an ethical climate alleviating moral distress would be one in which: 1) those experiencing distress see themselves as being heard and their distress as being taken seriously by their peers and a supportive administration;<sup>20, 21</sup> 2) the existence of organizational mission discernment and a mission statement to match;<sup>22, 23</sup> 3) open communication strategies;<sup>24, 25</sup> and 4) as noted above, moral distress education. Such an ethical climate would hopefully be one in which any health care professional experiencing moral distress would feel comfortable asking to have it addressed, knowing that the organization had created an environment conducive to doing so, based on the background of equality of health care professionals, moral

acquaintanceship, and discourse ethics that I have discussed.

<sup>1</sup> Bernadette M. Pauly, Colleen Varcoe, and Jan Storch, “Framing the Issues: Moral Distress in Health Care,” *HEC Forum*, 24(1) (2012): 1-11.

<sup>2</sup> American Association of Critical-Care Nurses (AACCN) Ethics Work Group, “The 4A’s to Rise above Moral Distress,” (N.P.: n.p.: 2004). Accessed 8/19/11.

[http://www.aacn.org/WD/Practice/Docs/4As\\_to\\_Rise\\_Above\\_Moral\\_Distress.pdf](http://www.aacn.org/WD/Practice/Docs/4As_to_Rise_Above_Moral_Distress.pdf), 1.

<sup>3</sup> Pauly et al. 2012, 2.

<sup>4</sup> Wendy Austin, Marlene Rankel, Leon Kagan, Vangie Bergum, and Gillian Lerner, “To Stay or to Go, to Speak or Stay Silent, to Act or Not to Act: Moral Distress as Experienced by Psychologists,” *Ethics and Behavior*, 15(3) (2005): 197-212.

<sup>5</sup> Wendy Austin, Marlene Rankel, Leon Kagan, and Vangie Bergum, “The Balancing Act: Psychiatrists’ Experience of Moral Distress,” *Medicine, Health Care and Philosophy* 11(1) (2008): 89-97.

<sup>6</sup> Sofia Kälvermark, Anna T. Höglund, Mats G. Hansson, Peter Westerholm, and Bengt Arnetz, “Living with Conflicts-Ethical Dilemmas and Moral Distress in the Health Care System,” *Social Science & Medicine* 58(6) (2004): 1075-84, 1077.

<sup>7</sup> Pauly et al. 2012, 1.

<sup>8</sup> These are the two most important priorities of health care organizations according to: David Ozar, Jessica Berg, Patricia H. Werhane, Linda Emanuel, and the AMA Working Group on the Ethics of Healthcare Organizations, “Organizational Ethics in Health Care: Toward a Model for Ethical Decision Making by Provider Organizations,” (Chicago: American Medical Association: 2001), 9-11.

<sup>9</sup> Judith F. Daar, “A Clash at the Bedside: Patient Autonomy vs. a Physician’s Professional Conscience,” *Hastings Law Journal* 44(6) (1993): 1241-89.

<sup>10</sup> Daar 1993, 1285.

<sup>11</sup> Daar 1993, 1285-86.

<sup>12</sup> This is not a “common moral framework” in any strong or “thick” sense. I am decidedly not claiming that this framework is THE answer to all moral quandaries. This is a looser shared

understanding, based on the shared moral obligations of health care professionals. In fact, “common moral framework” may not be the most exact term—if a different, more explicative term can be thought of, it will be used. One possibility is “shared convictions”. In addition to removing the objection that health care professionals do not, in fact, explicitly use a moral framework, this phrase implies that health care professionals are imbued with the same convictions about their role in health care, for example, respecting patient autonomy, healing the sick when possible, providing comfort, and so forth.

<sup>13</sup> Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics: Fifth Edition* (New York: Oxford University Press, 2001).

<sup>14</sup> Beauchamp and Childress 2001, 3.

<sup>15</sup> H. Tristram Engelhardt, Jr. *The Foundations of Bioethics: Second Edition* (New York: Oxford University Press, 1996).

<sup>16</sup> Kevin Wm. Wildes, *Moral Acquaintances: Methodology in Bioethics* (Notre Dame: University of Notre Dame Press, 2000).

<sup>17</sup> Wildes 2000, 139.

<sup>18</sup> Wildes 2000, 144.

<sup>19</sup> Cynda Hylton Rushton, “Defining and Addressing Moral Distress: Tools for Critical Care Nursing Leaders,” *AACN Advanced Critical Care* 17(2) (2006): 161-68, 166.

<sup>20</sup> Wendy Austin, “Moral Distress and the Contemporary Plight of Health Care Professionals,” *HEC Forum* 24(1) (2012): 27-38.

<sup>21</sup> Linda Olson, “Ethical Climate in Health Care Organizations,” *International Nursing Review* 42(3) (1995): 85-90.

<sup>22</sup> Stanley Joel Reiser, “The Ethical Life of Health Care Organizations,” *The Hastings Center Report* 24(6) (1994): 28-35.

<sup>23</sup> John A. Gallagher and Jerry Goodstein, “Fulfilling Institutional Responsibilities in Health Care: Organizational Ethics and the Role of Mission Discernment,” *Business Ethics Quarterly* 12(4) (2002): 433-50.

<sup>24</sup> David O. Renz and William B. Eddy, “Organizations, Ethics, and Health Care: Building an Ethics Infrastructure for a New Era,” *Bioethics Forum* 12(2) (1996): 29-39.

<sup>25</sup> Cindy H. Rushton and JoAnn Brooks-Brunn, “Environments that Support Ethical Practice,” *New Horizons* 5(1) (1997): 20-9.



# Quality Attestation for Clinical Ethics Consultants: Perspectives from the Field

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In the September-October 2013 issue of the *Hastings Center Report*, the Quality Attestation Presidential Task Force of the ASBH proposed a quality attestation process for clinical ethics consultants through the use of a portfolio and oral examination.<sup>1</sup> The Task Force is to be commended for navigating the debate in clinical ethics consultation (CEC) credentialing, certification, and accreditation through the use of this two-step model. I will focus my comments on the portfolio portion of the quality attestation model in order to provide clarification on its use and evaluation. More specifically, I will suggest that although portfolios do enable the evaluation of a candidate's skills and effectiveness, that candidate must have a clear understanding of the accepted parameters of professional competence in the field in order to construct the portfolio itself. This is an important clarification that must be explicit if a portfolio process is to be used such that an objective basis may be established for its evaluation.

Portfolio assessment has been in use in education for more than two decades.<sup>2</sup> In

that time, some consensus has developed as to the general content that should be represented in a portfolio that will illustrate the candidate's competency and skills. The Task Force has done an excellent job capturing the majority of the content areas that should be included in any portfolio designed to demonstrate competence and skill in CEC.<sup>3</sup> The Task Force has done this while accommodating the wide variation in the backgrounds and disciplines of those presently performing CEC. The Task Force also rightly notes that such variation is appropriate to accommodate so long as the "end result is within the accepted parameters of professional competence."<sup>4</sup>

Unfortunately the Task Force is not explicit as to whether the ASBH's *Core Competencies* is to serve as the accepted parameters of professional competence. They suggest that the *Core Competencies* serve as *an* outline for some widely accepted notion of the qualifications that permit a clinical ethics consultant to practice.<sup>5</sup> However, without stating explicitly that the *Core Competencies* will, for the purposes of the Task Force's recommendations, serve as the widely

accepted notion of the qualifications for CEC, the candidate is left to construct a

portfolio absent this critical understanding of what will serve as the basis for the evaluation of the portfolio itself. The danger here is that in casting the net wide to include the variation in the backgrounds and disciplines of those presently performing CEC, the Task Force may have too quickly sacrificed the tremendous work done to assess the *accepted* parameters of professional competence.<sup>6</sup> Two examples within the Required Elements for CEC Quality Attestation Portfolio serve to illustrate this point: (a) six case discussions of consultations, and (b) six one-page descriptions of *additional* cases that evidence CEC experience.

Among the required elements for a candidate's CEC Quality Attestation Portfolio are six case discussions of consultations in which the candidate acted as lead or co-lead and authored or coauthored documentation. Although the Task Force notes that "at a minimum, the following elements should be included in the write-up: case narrative, synopsis, relevant ethical issues, assessment, recommendation, and outcome,"<sup>7</sup> these recommended minimal standards are absent the substantive recommendations of the Core Skills and Knowledge for Clinical Ethics Consultation, of the Clinical Ethics Consultation Affairs (CECA) committee in 2009. Furthermore, to my point concerning the ambiguity about the role of the *Core Competencies* in relationship to accepted parameters of professional competence,

the Core Skills and Knowledge recommendations from the CECA based

its work on the *Core Competencies*. The substantive work of the CECA Report that gets precisely at the matter of what constitutes professional competence in both skill and knowledge should form the basis for the candidate's demonstration of professional competence in his or her case discussions. Secondly, with a nod to the *anticipated concerns* noted by the Task Force, the final portfolio element should address CEC experience on routine cases, rather than focus on CEC experience in relationship to a *range* of clinical settings.<sup>8</sup> In other words, quoting my own mentor, Dr. Glenn Regalie, "Common things are common." Thus, the candidate's one page descriptions of cases should focus on the types of cases that are often seen in CEC and/or on "settled" cases in the literature in an effort to truly assess professional competence and skill.

This raises a secondary issue for Catholic health care in that even if the Task Force did plan to utilize the *Core Competencies* document as the accepted parameter of professional competence, the *Core Competencies* alone may not address the entire scope of skills necessary for portfolio design and evaluation of ethicists working in Catholic health care.<sup>9</sup> Additional required elements will need to be added to the CEC Quality Attestation Portfolio for use in Catholic health care such as those found in the Catholic Health Association's, "Recommended Qualifications and Competencies for System Ethicists in Catholic Health Care

and for Facility/Clinical Ethicists in Catholic Health Care.”<sup>10</sup>

The idea of a two-step model for quality attestation for clinical ethics consultants is an elegant approach to identify individuals who are qualified to perform in this role. I agree with the authors that CEC is a “high stakes endeavor” with corresponding professional obligations for which a Quality Attestation Portfolio and Oral Examination is critical to the field.<sup>11</sup> I encourage the Task Force to reexamine or make more explicit the connection between substantive work done in this area on the matter of CEC skills and competencies among their ASBH colleagues and to form a necessary collaboration with CHA to expand its scope to include the significant number of ethicists working in Catholic health care who will require a more expanded and specific portfolio and oral examination process.

<sup>1</sup> Kodish, E *et al.*, “Quality Attestation for Clinical Ethics Consultants: A Two-Step Model from the American Society for Bioethics and Humanities,” *Hastings Center Report* 43, no. 5 (2013): 26-36.

<sup>2</sup> Seldin, P. *The Teaching Portfolio: A Practice Guide to Improved Performance and Promotion/Tenure Decisions*. 3<sup>rd</sup> Edition. (Bolton, MA: Anker, 2004). Also, 2<sup>nd</sup> Edition, 1997 and 1<sup>st</sup> Edition, 1991.

<sup>3</sup> Kodish, “Quality Attestation for Clinical Ethics Consultants,” 30; Hutchings, Pat, ed., *The Course Portfolio: How Faculty Can Examine Their Teaching to Advance Practice and Improve Student Learning*. (Washington, DC: American Association for Higher Education, 1998); and Urbach, F.

“Developing a Teaching Portfolio.” *College Teaching* 40 (1992): 71-74.

<sup>4</sup> Kodish, “Quality Attestation for Clinical Ethics Consultants,” 31.

<sup>5</sup> Kodish, “Quality Attestation for Clinical Ethics Consultants,” 29.

<sup>6</sup> Clinical Ethics Consultation Affairs Committee. “Report to the Board of Directors of the ASBH on Certification, Accreditation, and Credentialing (C/A/C) of Clinical Ethics Consultants.” *C/A/C Report* (October, 2010): Appendix B.

<sup>7</sup> Kodish, “Quality Attestation for Clinical Ethics Consultants,” 30, 31.

<sup>8</sup> The Task Force did make a general recommendation in the *Anticipated Concerns* portion of the *Hastings Center* article by suggesting that “We have sought to articulate standards commensurate with routine practice, not esoterica and not the complicated cases that become the object of academic dispute,” but did not reference this specifically in the “required elements” of the portfolio, see: Kodish, “Quality Attestation for Clinical Ethics Consultants,” 34.

<sup>9</sup> Hamel, R., Slosar, J.P., and Repenshek, M. “Answering the Call from ASBH’s Second Edition of Core Competencies in Ethics Consultation.” *AJOB* 13, no. 2 (February 2013): 18-19.

<sup>10</sup> CHA. “The Ethics Role in Catholic Health Care.” See: [www.chausa.org/docs/default-source/general-fildes/cha-ethicsrole-pdf?sfvrsn=2](http://www.chausa.org/docs/default-source/general-fildes/cha-ethicsrole-pdf?sfvrsn=2) access on January 6, 2014.

<sup>11</sup> Hamel, R. “Ethical Currents—Strengthening the Quality of Ethics Consultants and Consultation.” *HCEUSA* 21, no 4 (Fall 2013): 28-29; Repenshek, M. “Continuous Quality Improvement Initiatives in Ethics: A Proposed Communication Tool.” *HCEUSA* 20, no. 4 (Fall 2012): 2-12; Repenshek, M. “Attempting to Establish Standards in Ethics Consultation for Catholic Health Care: Moving Beyond a Beta Group.” *HCEUSA* 18, no. 1 (Winter 2010): 5-14.

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Any reader of *Quality Attestation for Clinical Ethics Consultation* who is familiar with clinical ethics consultation will share with the authors their basic premise: there is a need to ensure quality and quality improvement in the process of clinical ethics consultation. As the authors comment, this is the one activity that occurs within the health care setting for which the practitioners are neither licensed, credentialed, nor certified. The authors, I believe, are correct in asserting that there is a need to ensure the competence of practitioners engaged in this practice.

If they have the diagnosis correct, have they created an appropriate treatment plan? I suspect that the answer to that question entails a more detailed response. My first reaction to reading the essay was that this is the hospital standardization movement reborn. Readers of the Christopher Kaufmann's *Ministry and Meaning* will recall his discussion of the reaction of Catholic hospitals to the efforts of the American College of Surgeons to impose a set of patient care standards in all hospitals in which surgery was performed. Should Catholic hospitals accept a set of standards established by a secular organization? In the current situation the question needs to be posed whether the quality attestation process proposed by the American Society for Bioethics and the Humanities (ASBH)

can accommodate practitioners who perform case consultations in a manner consistent with the *Ethical and Religious Directives for Catholic Health Care Services*? Practitioners within Catholic hospitals may also be guided, at least in part, in the process of case consultation by core values such as compassion, human dignity and the sacredness of life. Are such religious and ethical guidelines consistent with the core competencies and skills set forth by the ASBH? That to my mind is an open question.

There is a second question that must be asked of the treatment plan designed by the ASBH. By what right or authority does ASBH claim hegemony over authenticating the practice of every one engaged in health care ethics consultation? They claim that commercial interests will enter this open market and that there is no other professional organization better equipped to meet this need within American health care. My underlying concern here is not so much directly focused on the ASBH, but rather that this entire effort conducted under the aegis of the ASBH is really a process of medicalizing health care ethics consultation. The quality attestation process is largely, although in fairness not exclusively, led by physicians. The need for health care ethics consultation arose, at least in part, to overcome the paternalism associated with the practice of medicine in the 1950s, 1960s and 1970s. Quality attestation falls somewhere between privileging and board certification, issues associated with the practice of medicine (27). A master's degree in a relevant discipline is required. There is no specified

training in ethics required for attestation. Ethics training is incidental to the requirements for attestation. Where professionally trained ethicists were instrumental in the development of health care ethics consultation, they are now to be replaced by medical professionals with incidental training in ethics. The oral review of the candidate's performance of case consultations is to be done in a manner similar to the "U.S. Medical Licensing Exam, Step 2 Clinical Skills Exam." Once again a medical model prevails. Health care ethics consultation occurs in a medical context, but it is not and should not be confused with the practice of medicine or medical decision-making. They are related but distinct functions.

The ASBH's *Core Competencies for Health Care Ethics Consultation* is an important contribution to the quality improvement of case consultation. Like the quality attestation process, it focuses on the qualities and expertise of the practitioner. There is another model for the improvement of health care ethics consultation that focuses not on the skills of the practitioner, but rather on the process or method of health care ethics consultations. The CASES methodology developed by the Center for Ethics in Health Care of the Veterans Administration is also an extremely important contribution to this conversation. Whether a focus on competencies and skills or a focus on methodology is more likely to enhance the quality of health care ethics consultation remains, at least to my mind, an open

question requiring significant further discussion.

I applaud the work of the ASBH. They have brought attention to an important quality issue within American health care. I think they have the diagnosis correct. However, I also think their treatment plan may require a second or third opinion. The methodological approach of the CASES model requires much further investigation. Perhaps a hybrid of a methodological approach with an emphasis on the skills and competencies of practitioners is where this discussion needs to go. Clarity regarding religious and cultural issues needs to be established. This is a profitable and productive conversation. It is too soon to cut it off.

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In the September-October 2013 issue of the *Hastings Center Report*, Eric Kodish, Joseph Fins, and associates propose that, given the importance of clinical ethics consultation to patient care, those doing it should be asked to show they do it well.<sup>1</sup> This is the latest development in the field of clinical ethics consultation, which probably began with the formation of the Society for Bioethics Consultation in 1986. When that body merged with two other bioethics associations to form the American Society for Bioethics and Humanities (ASBH) in 1998, strong

support for clinical ethics consultation continued in the new organization.

A guide to basic skills and knowledge necessary for competent clinical ethics consultation was published by ASBH in October of that same year and updated with a slightly different title in 2010.<sup>2</sup> In 2008, the ASBH president initiated the Clinical Ethics Consultation Affairs (CECA) standing committee to advise the board on issues related to health care ethics, including the topic of certifying health care ethics consultants. In 2009, ASBH published another resource, *Improving Competencies in Clinical Ethics Consultation*.

Do you hear that clattering noise? It's the sound of a field professionalizing. Like the dry bones in Ezekiel, these are the bones of a new specialty, over time assembling into what will become the culture and practice of professionals who are trained, experienced, certified in and good at clinical ethics consultation. There will be life in those bones.

We are now at the beginning of that process. As with anything in the nascent stages, how all the parts fit together and what the final version will look like is not absolutely clear. Here are some questions that don't seem to be settled yet.

**What constitutes good quality in ethics consultation?** We know what detracts from a good consult: a consultant with an enlarged ego; insufficient time or lack of clarity about the goal of a consultation (both of which are implicated in the 'curbside consult'); inadequate knowledge

of ethical norms or the law; inability to facilitate discussion among the interested parties. These are just a few quality dampeners in clinical ethics consultation. But if the opposite of these are present—a modest and well-prepared consultant or team, adequate time and clarity of goals, ability to facilitate compassionately—do we know what makes a good consult? Do we measure it by the outcome, by the family's satisfaction, the clinician's satisfaction or a combination of all three? Is it purely procedural?

**How should consultants prepare themselves?** As it is now, clinicians become consultants in a range of ways. Some have been on their ethics committees for a long time, and have repeatedly been asked to help at the bedside. Over time, these have become persons of practical wisdom. Others have attended accredited programs, where book learning is combined with mentored experiences, getting the kind of supervision a chaplain resident or social worker gets on the way to certification in those professions. This type of preparation may more deliberately give a person the philosophy and language the Quality Attestation process looks for. It may or may not make a better consultant.

**What will happen in hospitals without a certified clinical ethics consultant?** The effort to improve the quality of ethics consultations is a good one and the research is certainly there indicating that quality varies in consultation. We know that some people doing consultations do it better than others. What we don't know is whether some consultation is better than

none. If people who do not have a sufficiently robust practice in ethics consultation to become certified simply stop consulting, it's not obvious that patients, families, doctors, nurses and others who currently take advantage of "uncertified" clinical ethics consultation are better off.

### Lingering questions

Dignity Health has forty hospitals, and experienced ethics committees in each. Of the dozen or so individuals who sent a letter of intent to submit a portfolio (the first step in the QA process), all five who were 'randomly' chosen to proceed were men. If those who refine the process are mostly of one gender, there may be a skewed viewpoint in the resulting attestation process. In the second step, the oral examination is planned to take place at the annual meeting of the ASBH. Tight budgets and travel costs may make it less likely for people to be able to enter that second stage.

As with any developing field, whether it's emergency medicine, palliative care or clinical ethics consultation, things take time. These are some of the questions we hope are answered as the bones of the QA process come to life.

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<sup>1</sup> Eric Kodish and Joseph J. Fins with Clarence Braddock III, Felicia Cohn, Nancy Neveloff Dubler, Marion Danis, Arthur R. Derse, Robert A. Pearlman, Martin Smith, Anita Tarzian, Stuart Youngner, and Mark G. Kuczewski, "Quality Attestation for Clinical Ethics Consultants: A Two-Step Model from the American Society for Bioethics and Humanities," *Hastings Center Report* 43, no. 5 (2013): 26-36.

<sup>2</sup> ASBH's *Core Competencies for Clinical Ethics Consultation* (1998) became its *Core Competencies for Health Care Ethics Consultation* in 2010, a 57 page monograph with four sections.

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### Introduction

There is a discrepancy in how one demonstrates professional competencies between clinicians and ethicists. Ethicists heretofore have had no credentialing or licensure process governed by a professional agency. With a degree of irony, unlike physician and nurse colleagues, ethicists do not have a code of ethics. These hallmarks of a health profession are guideposts that inform institutions in privileging and credentialing providers. Their lack in the field of ethics signifies a gap in demonstrating to institutions and the community at large accountability and professionalism in ethics.

Moreover, much ink has been used in attempting to describe and establish quality standards in the performance of ethics consultation. Various metrics have been proposed, but with different definitions of practice, no consensus around conducting ethics consults (save for a few 'emerging standards'), variable structures and personnel doing the work, and no accountability to regulatory agencies (governmental or not, tied to

reimbursement or not), the likelihood of externally binding standards remains elusive.

In this context, the American Society for Bioethics and Humanities (ASBH) charged a task force with the responsibility of crafting a process to assess ethics consultants' competency as a mechanism of ensuring quality in ethics consultation.<sup>1</sup> This effort is in addition to the development and publication of the recommended competencies for health care ethics consultation.<sup>2</sup> For its part, CHA sought to enhance the conversation around competencies and quality in ethics for Catholic health ministries.<sup>3</sup> The ASBH quality attestation process described is a valiant effort to bring dimensions of accountability and professionalism to those who practice ethics consultation in health care, but it raises many questions and may have limited import to the work of ethics in Catholic health care.

### Quality Attestation & Quality Improvement

On the one hand, I agree with the basic premise of the quality attestation process. That is, quality improvement is important for ethics consultation services. Furthermore, I agree that the competencies of those doing ethics work is essential to having confidence in consistent quality consultation services.

The quality attestation process as described is robust and as such a good exercise for those engaged in and managing the work, especially for those early in their ethics careers. The quality

attestation portfolio (step 1) and oral examination (step 2) reflects - in a rigorous way - the approach with which I am familiar regarding hiring ethicists. It remains to be seen, however, whether the desire for inclusiveness waters down meaningfulness of the process; and whether such "attestations" are transferable from institution to institution, or setting to setting.

On the other hand, as suggested, there is much to wonder about with the ASBH quality attestation (QA) process. While diversity (of ethical methodology) has long been claimed as a value-added characteristic of ethics consultation in general, I wonder whether there is simply too much variance. Clinical ethics consultation is not a panacea; so being overly inclusive is a hazard that dilutes what "it" really is. In part, what prompts my worry here is that often an ethics consult is requested without a clear ethical issue.<sup>4</sup> This does not mean an ethics consult is inappropriate, but it does suggest to me that the frameworks and taxonomies used in health care ethics may be inaccurate and imprecise, which makes any quality initiative a difficult task because the proverbial cart is before the horse. As another example, in our institution, we tend to view ethics consultation more as coaching and less as advisement. This view contrasts with other perspectives wherein ethics consultation is precisely advisement or mediation or conflict resolution.<sup>5</sup>

In addition, the QA process seems to equivocate quality *services* with competency of *professionals*. While they



are intimately related, I would not want to reduce one to the other. To my mind, through demonstrating competency in a QA process, an institution may trust an ethicist or ethics consultant in much the same way it might put trust in a provider privileged to perform certain procedures. Perhaps the connection between competency and quality is based on this kind of confidence, but this does not appear to be an explicit connection.

Lastly, the QA process does not make clear how it might be used when assessing team competencies. As suggested in the *Core Competencies*, ethics consultation teams exist and ideally must demonstrate, in total, the range of competencies required. In fact, data suggest that the team approach to consultation is most common and that the individual consultant approach is least common.<sup>6</sup> This begs the question of how one might translate the QA process to team-focused evaluation.

### Implications for Catholic Health Care

The QA process, as inclusive as it strives to be, does not emphasize the importance of theological competency, which is a core competency of doing ethics in a Catholic health ministry.<sup>7</sup> Moreover, the QA process presupposes institutional capabilities and standards, which may require operational adjustments (e.g., hiring an ethicist). This is complicated by the fact that different ministries have access to variable resources both in terms of operational budget and philanthropy to help keep ethics services solvent. Many ministries have personnel that are trained for one role (mission integration or

spiritual care) but also have ethics-related responsibilities; such individuals may or may not have sufficient training or experience in ethics.

That said, the QA process may have more value for demonstrating the competencies of those engaged in clinical ethics consultation (vs. organizational ethics) as this may be more comparable between Catholic and non-Catholic settings. Nevertheless, there are still select clinical circumstances that would require a degree of theological skill and knowledge, as in perinatal and obstetric settings as well as in locations where physician-assisted suicide is legally available.

### Lingering Questions

In addition to some issues I raised above, there are other, broader questions I have. For example, it is not clear how this process will incorporate, embrace, or adjust (if at all) to the transformations that are occurring in health care today. Will ethicists attest to competencies that cultivate ethical decision-making in the setting of population health and across institutions? That said, I applaud the group for having the courage to seize this “confluence” of factors to move in *some* direction on standards of competencies. They should remain steadfast because there will be many more critics, some of whom may be vigorous. It will remain a daunting task. There are many factors out there that may mitigate the group’s success.

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<sup>1</sup> Eric Kodish, Joseph J. Fins, et al., “Quality Attestation for Clinical Ethics Consultants: A Two-Step Model from the American Society

for Bioethics and Humanities,” *Hastings Center Report*, Sep-Oct 2013, 43 (5): 26-36.

<sup>2</sup> ASBH, *Core Competencies for Health Care Ethics Consultants*, 2nd edition (Glenview, IL: ASBH, 2011).

<sup>3</sup> Catholic Health Association of the United States, *Striving for Excellence in Ethics: A Resource for the Catholic Health Ministry*, <http://www.chausa.org/ethics>, (St. Louis, MO: Catholic Health Association and Ascension Health, 2011).

<sup>4</sup> Susan E. Kelly, et al., “Understanding the Practice of Ethics Consultation: Results of an Ethnographic Multi-Site Study,” *Journal of Clinical Ethics*, Summer 1997, 8 (2): 136-149.

<sup>5</sup> John Tuohey and Nicholas Kockler, “Aconselhamento ou “coaching”? A consultoria ética no contexto da pós-graduação em educação médica [Counseling or “coaching”? The advice ethics in the context of graduate medical education]”, in *Ética e Bioética Clínica no Pluralismo e Diversidade: teorias, experiências e perspectivas, Proceedings from the 8th International Conference on Clinical Ethics Consultation* (São Paulo, Brasil), May 2012, 115-131.

<sup>6</sup> Ellen Fox, et al., “Ethics Consultation in United States Hospitals: A National Survey,” *American Journal of Bioethics*, February 2007, 7 (2): 13-25.

<sup>7</sup> Cf. “Recommended Qualifications and Competencies for Facility/Clinical Ethicists in Catholic Health Care,”

[www.chausa.org/careers/careers-in-ethics](http://www.chausa.org/careers/careers-in-ethics), accessed 10-January-2014; and

“Recommended Qualifications and Competencies for System Ethicists in Catholic Health Care,”

[www.chausa.org/careers/careers-in-ethics](http://www.chausa.org/careers/careers-in-ethics), accessed 10-January-2014.

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When I began my bioethics training at the Medical College of Wisconsin in the 1990s, the masters' degree was a robust 42-credit course of study. All instruction was on-site at MCW and clinical practice was conducted under the tutelage of experienced MCW physicians at the many affiliated institutions. The coursework included health care law, epidemiology, biostatistics, along with theory and clinical practice related to bioethics. There was also a strong teaching component as our cohort led class discussions, presented grand rounds, and conducted case reviews for the teaching hospital's ethics committee. The ethics consultation course was by invitation of the faculty for students who demonstrated aptitude in the subject matter as well as the appropriate temperament to engage in this difficult work with anxious families and often frustrated physicians.

In the past 15 years, we have seen the proliferation of abbreviated degrees (30 credits seems to be most common) and online instruction where students only rarely, if ever, have in-person instruction and training. The field has opened up to those not living in the vicinity of an academic medical center with a bioethics department. This has made training accessible to physicians and other clinicians in smaller communities and rural areas, which is to be celebrated. At

the same time, a degree of any level, including doctoral, which does not include significant clinical practice, cannot be assumed to confer the many intangibles that are necessary for competence to conduct CEC. I was pleased to read that there is another initiative assessing bioethics training programs and fellowships from the Association of Bioethics Program Directors.

ASBH is to be commended for its respect for the variety of disciplines represented in the field, and the task of developing a standard for quality attestation is indeed a daunting one. Even with the proposed model it will be difficult to measure such attributes as the ability to make connections with all types of people, the openness to reconsidering one's own position, and an appreciation for and ability to work with the nuances involved in hospital politics.

I agree with the incremental approach to making attestation the standard, and would suggest some deliberation in these areas:

- The preparation of a portfolio for review appears to be a major undertaking even for those working daily in the field of clinical ethics. Those who provide consultation as part of a team, and in addition to other work in health care, may not have the volume of cases necessary, or the inclination to assemble a portfolio, while

those who are new to the field may be interested in acquiring an attestation of their abilities, but also may lack adequate experience. What inducement will there be for those experienced in CEC to do the work of preparing the portfolio and submitting to an oral examination? How can those with newly minted degrees gain the requisite experience?

- How will attestation be promoted so that it will come to be valued by senior leaders in health care?
- Will there be any variation in what areas of experience are required? For example, those working in regional medical centers or teaching hospitals may need a higher threshold of clinical literacy than those working exclusively in long-term care.
- According to the American Hospital Association, there are 630 Catholic hospitals in the U.S. accounting for 15 percent of the hospital beds. There are many hundreds more nursing homes, hospice programs and clinics operating under Catholic sponsorship. HCEUSA readers are well aware of the additional areas of competency necessary for doing

CEC in a Catholic facility including a deep understanding of the *Ethical and Religious Directives for Catholic Health Care Services* and literacy in moral theology. This is obviously outside the scope of ASBH, but it is very important. How might it be addressed?

The need to prepare the next generation of CECs is clear from the statistics regarding the ages of many currently practicing in the field. A systematic approach to quality attestation to guide that preparation will be a good beginning.

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As a member of the American Society for Bioethics and Humanities (ASBH) and the ASBH Clinical Ethics Consultation Affinity Group (CECAG), I have been following the discussions surrounding Quality Attestation (QA) of Clinical Ethics Consultants and the development of the Code of Ethics with great interest. In my role as director of ethics at a 600+ bed Catholic teaching hospital, I wonder how this QA process will impact the development of ethics consultants locally, at a system level, and throughout Catholic health care as well as those just entering the field. I also wonder whether there

ought to be a similar quality attestation in Catholic health care and, if so, whether it ought to extend beyond consultation to provide direct QA also of education and policy development and review. While it would certainly include the *Ethical and Religious Directives* (ERDs) and matters of cooperation and scandal, it would also extend to other critical areas of the ministry of health care, engaging the health care ministry's response to the common good, linking Catholic social teachings and the church's moral tradition.

I agree with the authors of QA that the historic dearth of a standard quality measure for those engaging in clinical ethics consultation (CEC) is no longer acceptable. The lack of a license or board certification such as those held by our physician colleagues or the CPE of our pastoral care colleagues can leave those who inquire about the qualifications of ethics consultants mystified, or worse, questioning our suitability for the work in which we engage. We build relationships with our colleagues and through that our professional reputations and identities over time. Yet the encounters we have with patients, families, and others are comparatively short and often occur in high stakes life and death situations. If questioned about our qualifications in that moment, a statement like "I have a Certificate/Masters/Ph.D. in philosophy/theology/public health" may not provide the inquirer with the answer for which they had hoped and may not inspire confidence or even assure competence. An inability to offer evidence of any formal training in ethics

may be even more problematic. Just as many of our colleagues are uncertain of what it is we do, the public may also be unsure and even suspicious of ethics consultation as talk of death panels and rationing swirls episodically in the media and in the blogosphere. The lack of QA may even impact our ability to justify the hiring or training of (additional) ethics consultants. The financial support of an ethics program, even for educational resources, may be impacted, as well as the quality of the program. Individuals or institutions may feel the amount of time spent doing ethics consultation due to a small number of consultations does not justify the time and (inevitable) cost to seek QA.

#### **Implications for Catholic Health Care**

The Catholic health care ministry is challenged in the face of this development to discern whether to endorse this QA as necessary or as a mark of excellence in an ethics program and whether, if it is necessary, it is also sufficient. Are the skills necessary for CEC in the setting of Catholic health care significantly different? Or is there simply an additional body of knowledge required in theology and the church's moral tradition? Could a similar process in Catholic institutions be seen as a litmus test for Catholic identity or the alignment of an ethics consultant with church teaching? What about those whose practice (or even a single consultation that occurs across the care continuum) spans multiple dioceses? Would a *mandatum a la Ex Corde Ecclesiae* or something similar be sufficient or even appropriate? Catholic health care ethicists draw from the moral tradition of

the church when they educate patients, families, and staff. Does this amount to an excursion into theology?

Just as the Catholic Health Association (CHA) continues to develop and refine its standards for “Excellence in Ethics” in response to the ASBH’s Core Competencies in Ethics Consultation, I believe that Catholic health care will also have to develop its own quality measures for those engaged in CEC. There are many matters that ethics consultants in Catholic health care are called to assess that those in non-Catholic settings may not even consider as ethical issues or would handle in a strikingly different manner. The moral distress of staff when they feel the ERDs are being violated or a practice is occurring contrary to our Catholic identity is profound. There is a particular skill for example in supporting staff in understanding the tradition and how a particular act is or is not supported by that tradition, i.e., that an intervention in a situation of maternal fetal conflict that results in the delivery (and death) of a preivable infant does not constitute direct abortion. Those involved in these decisions must be educated about intentionality and the importance of language. An intention and expression of the necessity of aborting an infant to save the life of a mother is quite different than the continuation of labor/delivery of a preivable infant in order to address a cure of a proportionately serious pathological condition of a pregnant woman.

If the ASBH QA becomes the norm in health care for those doing ethics consultation, there may be increased liability if Catholic health care does not require the ASBH QA, regardless of whether any other QA or similar process is required by Catholic health care. Often Catholic hospitals are called to articulate that our care of women in cases of sexual assault or maternal fetal conflict is the same standard of care provided in non-Catholic institutions. Within this hermeneutic of suspicion, if ethics consultants in Catholic health care do not obtain the ASBH QA will this too be seen as negligent or subpar? Unlike ASBH there is not a similar national association of Catholic health care ethicists. What sort of body in Catholic health care would administer QA? An additional challenge that ASBH may not face with its hundreds of members which provides a large pool of unbiased examiners is the comparatively smaller and tight knit community of those working in Catholic health care ethics. Many of us work together and collaborate regularly. Many of us trained in the same programs. A large number of us were/are faculty or mentors of one another which could compromise objectivity.

The ASBH QA process requires the examination of these and many other questions by the Catholic health care ministry. Like the ASBH process, I expect that it will take many years and will not be without controversy. Yet we must begin this conversation in earnest lest someone else do it for us.

## Ethics Matters

### *Evangelii Gaudium*

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Pope Francis' apostolic exhortation, *Evangelii Gaudium*, is a clarion call to the people of God and to the leadership of the Catholic health care ministry. In this document, the Pope calls the Church to a recommitment to the task of evangelization, by which he means the cultivation within the Church and within society and culture of the significance and meaning of brotherly love. The Pope "dreams of a missionary 'option', that is a missionary impulse capable of transforming everything so that the Church's customs, ways of doing things, times and schedules, language and structures can be suitably channeled for the evangelization of today's world rather than her self-preservation." (27) For Pope Francis the unity of the love of God and neighbor, brotherly love are the centerpiece of the the kerymga, the message of the Gospel.

This call to evangelization should not be confused with proselytization, nor should it be confused with the task of childhood learning of catechism. Evangelization, as Pope Francis envisions it, is the task of discerning the meaning of brotherly love so that it has significance for women and men engaged in the tasks of supporting a family, contributing to a domestic

economy and shaping a world which is reflective of a socially and culturally appropriate enactment of the common good. Evangelization is not about theories. Evangelization is about the manner in which the Gospels, particularly love of neighbor, can be relevant in the day-to-day lives of persons within and outside of the Church. Evangelization is about how Christians live and the witness that their lives can be to the many others with whom they are joined by bonds of culture and social structures.

And what is the role of the Catholic health care ministry in the task of evangelization? No section of *Evangelii Gaudium* is directed explicitly to the Church's health care ministry, nor to any other specialized ministry such as education or social work. However, Pope Francis does speak about other Church institutions "as a source of enrichment for the Church, raised by the Spirit for evangelizing different areas and sectors." (29) The area or population served by the American Catholic health care ministry can, perhaps, best be defined as the vulnerable. Persons present themselves to the ministry because they are vulnerable, they are sick, they are dying, they are victims of trauma. Persons come to the ministry because to some

extent and in some manner they are losing control of a dimension of their being. They are frightened and afraid. In an era in which the model of care is focused on wellness and the prevention of mortality and morbidity, the ministry should not lose sight of the fact that the focus on wellness is defined over and against mortality and morbidity. The best preventive care imaginable must ultimately yield to the inevitability of mortality.

The task of evangelization associated with the Church's health care ministry is to engage the vulnerability, the morbidity and mortality associated with life. In some ways this is not a new task. Compassion, respect for human dignity and the sanctity of human life are each traditional efforts to engage the vulnerability of patients. But I think Pope Francis is calling the ministry to something new and something more challenging. The call is first to articulate what the meaning of brotherly love entails, what the unity of love of God and love of neighbor means in the context of this ministry. This is a daunting task for leaders of the ministry. The task is daunting because it is not about talking about love of God and love of neighbor, but rather it is about shaping the engagements of patients with caregivers so that love is mediated in these engagements. Evangelization is about meaning. Thus the litmus test of the success of evangelization in the health care ministry rests with the experience of patients and families. Evangelization is not about theory, but about creating meaning

that can sustain the faith and well-being of the vulnerable.

Evangelization may appear to be a very explicitly Christian, even Catholic concern. However, brotherly love and the unity of love of God and neighbor are not uniquely Christian or Catholic tenets of faith. The good deeds of our Jewish colleagues and the role of the fifth pillar of Islam for our Muslim colleagues all converge in a common element shared by these three faith traditions. The ministry brings together an array of women and men of a variety of religious faiths. The bond that holds all of us together in a common ministry is not simply the clinical and professional skills that we bring to the ministry, as important as these skills are, but rather our shared commitment to provide meaning to the vulnerable who come to us for care.



# Financial Responsibility for Study-Related Injury

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## *A Key Research Ethics Issue*

Recently, an Institutional Review Board (IRB) chairperson remarked that many research proposals are shifting financial responsibility for participant research-related injury from the study sponsor to the participant. That is, if a person agrees to participate in medical research, the cost of adverse events, such as infection and medication reactions, may fall on the participant.

Federal research grant funds do not cover compensation for injuries and recently many privately funded research protocols include a statement of no financial responsibility related to subject injuries.

This trend raises a serious question of organizational responsibility:

- Should IRBs approve protocols that disavow sponsor or researcher financial responsibility if the participant needs medical care as a result of participating in the study?

IRBs exist primarily to protect against the abuse of study subjects. The years following World War II through the 1960s brought to light many unethical research studies conducted abroad and in the United States. The Nazi atrocities, along with extreme cases in America, such

as the Tuskegee Syphilis Study and the Willowbrook Hepatitis Study, left the world demanding some regulation and oversight of medical research.

By 1972, the demand for ethical oversight of human-subjects research led the United States Congress to pass The National Research Act, which established IRBs. A study involving human subjects must be approved by an IRB before it can proceed.

- While the IRB's role in human medical research entails examination of study design, conflicts of interest, and scientific due diligence, the primary role of IRBs is protection of vulnerable participant populations and ensuring respect for persons.
- When a facility IRB approves a study, it is essentially stating that the study is legitimate in its design and protocol – that it is just, fair, and ethically appropriate.

One major aspect of research that IRBs scrutinize is informed consent. This process, through which a study participant receives information about possible study risks, benefits, alternatives, and voluntary participation, also includes information about medical liability.

The informed consent documentation is one place IRBs look to understand how adverse events will be handled.

### Participant Consent Is Not Enough

Some researchers assert that the informed consent documentation allows the participant the opportunity to refuse to take part if she considers the risk too great, and thus, researchers and sponsors have fulfilled their obligation to protect the subject.

This argument is flawed on at least three related points:

1. This assertion assumes that anything a study participant agrees to is, thereby, ethically justifiable. Some research and some research agreements do not meet ethics standards even if the informed consent process is clear and the sponsor, researcher, and participant find the arrangement acceptable.
  - One example is the Tuskegee Syphilis Study. Study participants were deceived and left untreated for known syphilis for many years. Even if the study participants had not been deceived, if they had been informed that their disease might not be treated, the study would still have failed by ethical standards because a safe, effective, inexpensive treatment for syphilis existed, and the study intentionally caused unnecessary harm.
  - No responsible IRB would approve of such a study simply because participants were informed and willingly agreed to be left untreated.

2. The second point follows from the first. Informed consent requires a reasonable sophisticated level of abstract understanding and analysis. A participant may not have adequate comprehension of risk and its future implications in terms of monetary cost, physical disability, and personal relationships.

Further, even if a participant does understand risks quite fully, the voluntariness of participation may be influenced by the circumstances. There is an imbalance of power and influence between the doctor/researcher and the patient/study participant.

Even when the researcher does not wish or intend to engage in undue influence, prospective participants, who look to physicians and other researchers as subject matter experts and guardians of health, may decide to participate out of a sense of loyalty, duty, respect, or confusion.

Their informed consent may be adequate when the risk is low, but the fact that there is a signed consent form does not mean, by itself, that the participant understands fully and accepts willingly the fact that the sponsor is disavowing financial responsibility for injury-related costs.

3. The third point is the assertion that informed consent *is sufficient* assumes that the patient understands the difference between research and therapeutic interventions.

Research protocols are designed *primarily* to achieve the sponsor's goals, but an individual may enter into a research protocol as an existing patient in a practice with no change in clinical site or addition of medical and research personnel.

In that circumstance, participants often see themselves as patients primarily, and only secondarily as study subjects. The roles of study subject and researcher need to be clearly defined. Patients who become study participants frequently do so in hope of an improved outcome.

If the primary intended benefit is to scientific knowledge and not to the patient/subject, this must be clear and explicit. This is not always the case.

### Protection of Subjects

According to a 2012 *American Society of Law, Medicine and Ethics* publication, the U.S. lags behind other research-intensive countries by lacking mandatory systematic compensation for research-related injury: “[B]y not requiring systematic compensation, the United States has become a moral outlier and risks having important biomedical advances delayed.”<sup>1</sup>

- While the U.S. has not yet passed legislation requiring systematic compensation, the topic has certainly received attention at very high levels.

Since 1973, many national advisory committees have concluded that study subject compensation for injury should be mandated in the United States. In 2011, The Presidential Commission for the Study of Bioethical Issues reiterated this need and also stated that the United States tort system is inadequate to address the problem.<sup>2</sup>

One reason that the tort system is inadequate to address subjects’ needs is that the injured person

would need to provide proof that study participation was the cause of the injury.

Considering today’s interdependent technologies and all of the possible ways injury can occur, the requirement of causality creates an unreasonable burden on the participant.

For this reason, most countries participate in no-fault systems, in which full coverage for study-related injury is included without proving causality.

### What Should the IRB Do?

Getting back to the original question, should IRBs approve research that is otherwise ethically satisfactory but does not provide participant compensation for study-related medical harm?

- The above commentary points toward a NO answer. In principle, all study participants should be covered for injury. But the question of who provides that coverage might be open to negotiation.

Sometimes an IRB position on subject protection can lead to the modification of a submitted protocol; sometimes other ways of assuring compensation for possible subject injuries can be found.

- Until the U.S. establishes a no-fault systematic compensation program for research subjects, many organizations will be left with difficult choices, and some research might just have to wait.

*This ethics reflection was submitted by Leonard J. Weber, Ph.D. and Kelly Stuart, M.D., and represents the views of Dr. Weber and Dr. Stuart.*

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<sup>1</sup> *American Journal of Law and Medicine*, 38:1 (2012):40.

<sup>2</sup> *Ibid.*, 18.

## Obstetric Complications in Catholic Hospitals

Catholic health care has taken a beating over the past few months, especially the way it supposedly manages obstetric complications due to its adherence to the *Ethical and Religious Directives for Catholic Health Care Services* (ERDs). Articles and editorials have appeared in the *New York Times*, the *Washington Post*, the *Los Angeles Times*, numerous local newspapers, various blogs, the *New Republic* and a good number of other publications. Most of these were reporting the ACLU's lawsuit against the United States Conference of Catholic Bishops (USCCB) as issuers of the ERDs. Then, of course, there was the release of the ACLU's and MergerWatch's report in December 2013, "Miscarriage of Medicine: The Growth of Catholic Hospitals and the Threat to Reproductive Health Care."

Attacks have come not only from the popular media, but also from more professional sources. Mentioned in a number of the popular media accounts was reference to the work of Lori Freedman, a professor at the University of California, San Francisco and Debra Stulberg, a physician in the Department of Family Medicine and the Department of Obstetrics & Gynecology at the University of Chicago. Several of their articles/studies were quoted or alluded to and given considerable credence. Freeman delivered a paper at the October 2013 meeting of the American Society for Bioethics and Humanities where she took Catholic health care to task and Freedman

and Stulberg together published an article in the October-December 2013 issue of *AJOB Primary Research*. Because they seem to be fairly influential, their work deserves closer scrutiny.

In 2010, Stulberg published an article in the *Journal of General Internal Medicine* (25, no. 7, pp. 725-30) titled, "Religious Hospitals and Primary Care Physicians: Conflicts over Policies for Patient Care." Of the 879 eligible physicians who received the study questionnaire, 445 (51 percent) responded. Of these, 191 (43 percent) had worked in religiously affiliated hospitals and, of these, 36 (19 percent) had experienced conflict over religiously based policies. In the discussion, the author states: "We found that almost half of primary care physicians have worked in a religiously affiliated hospital or practice, and among these physicians, approximately one in five has had conflicts with the institution's religiously based patient care policies" (728). Several observations:

- This wording gives the impression that almost half of *all* primary care physicians in the country have worked in religiously affiliated hospitals or practices, and that one in five of *all* primary care physicians in the country have had a conflict. But, in fact, only 19 percent of the primary care physicians who *responded to the survey* and have worked in religiously affiliated hospitals or practices have had a conflict, for a total of 36. And not all of these

- worked in Catholic health care facilities. Can one legitimately generalize on the basis of the experience of 36 primary care physicians that policy conflicts in religiously based hospitals are a widespread problem?
- The study provides no information about the nature of the conflicts, whether they were actually due to institutional policies or to other factors, or their number or frequency. This would seem to be important information in order to obtain an accurate assessment of the situation and its seriousness. In some instances, it could be that the physician objected to a policy that was more “liberal” than his or her personal views or that the conflict was between the physician’s personal views (rather than the standard of care or a medical judgment) and institutional policies. Also, does it matter whether a physician had one such conflict over 20 years or has had 30 conflicts over five years? This is not addressed.
  - The study tells us nothing about which religiously based policies were the source of conflict and which were most often the source of conflict.
  - As a point of comparison, it would be interesting to know whether primary care physicians in non-religiously based hospitals and practices have had conflicts with institutional policies and which ones.
  - In concluding the article, the author writes: “[T]hese results suggest that a significant minority of primary care physicians working in religiously affiliated health care institutions has faced conflict over religious policies for patient care” (730). Can one legitimately make such a generalization on the basis of 36 physicians?
  - Based on the study findings, the author concludes: “Policy-makers may find physicians’ experiences reported here useful in addressing the role of religious institutions in the delivery of health care” (730). This seems like a significant jump—from a few religiously-based policies that cause conflict to the role of religious institutions in the delivery of health care. It’s not clear how one legitimately moves from one to the other.
- The article that was most frequently mentioned in newspaper stories and blogs was a 2012 article, “Obstetrician-Gynecologists, Religious Institutions, and Conflicts Regarding Patient-Care Policies,” published by Debra Stulberg and colleagues in the *American Journal of Obstetrics and Gynecology* (207: 73e1-5). This study surveyed 1,128 ob-gyns, described as a nationally representative sample. The purpose of the survey was

twofold: a) to identify those who practice in religiously affiliated institutions and to

determine the prevalence of physician-institution conflicts over religiously based policies for patient care, and b) to measure the number of obstetrician-gynecologists who said that policies in their institutions limited their options for treatment of ectopic pregnancy (73.e2).

Regarding (a), approximately 241 (22 percent) of the 1,128 physicians surveyed practiced primarily in religiously affiliated institutions. 143 (59 percent) of these practiced in Catholic health care facilities. 90 (37 percent) of the 241 physicians who work primarily in religious institutions have had conflicts with their institution over religiously based policies. 74 (52 percent) of those who work in Catholic institutions have had such conflicts. Regarding (b), the author writes: “With respect to the treatment of an ectopic pregnancy with fetal heart tones present, the great majority of obstetricians-gynecologists would be willing to perform a salpingectomy and/or a salpingostomy. Furthermore, few physicians (n=31; 2.9 percent) reported that policies of their institution limit the options that they have for the treatment of ectopic pregnancy in similar cases: 2.5 percent of those who work in non-Catholic institutions vs. 5.5 percent in Catholic institutions (P=.07)” (73.e4).

In the Comment section of the paper, the authors write: “Based on obstetrician-gynecologists’ experiences, hospital policies frequently do not restrict options

for the treatment of ectopic pregnancy. Although physicians at Catholic hospitals were slightly more likely (p=.07) to report institutional restrictions than those at

non-Catholic hospitals, restrictions were uncommon in all institutions. These findings suggest that, although Catholic ethicists debate whether the use of salpingostomy and methotrexate constitute direct abortion, few institutions prohibit these practices. Confusion on this issue ....” (73. e4-e5). Again, a few observations:

- While the article title refers to “religious institutions,” a great deal of space is devoted to Catholic health care facilities. This doesn’t seem to be an even-handed treatment.
- The authors make note of the fact that in the past many Catholic ethicists interpreted Catholic teaching as banning any direct treatment of ectopic pregnancy unless the fallopian tube had ruptured. While this is true, this position has not been held since 1933, yet the authors make it sound like it was held in the not too distant past, thereby, conveying a false impression.
- The authors also refer to the debate among Catholic ethicists about the moral permissibility of salpingostomy and methotrexate (though as evidence of this they cite one article for each position). While there are differing views

among ethicists today, this is not a pressing debate and the general consensus is that both are morally permissible. The authors' account raises questions about how familiar they are with Catholic moral teaching and with what actually goes on in Catholic health care.

- The authors conclude the article by stating that “[T]his study suggests that conflict over religiously based patient care policies is common among obstetricians-gynecologists who work in religiously affiliated institutions, particularly Catholic institutions” (73.e5). Does 37 percent make it common? 52 percent? And, again, we don’t know the frequency of these conflicts. What makes such conflicts “common” is frequency over time for each individual. The fact that 74 obstetrician-gynecologists have experienced a conflict with institutional religiously based patient care policies out of how many ob-gyns who practice in Catholic health care does not make such conflicts “common.” The authors seem to be reading their pre-conceived conclusions into the data.
- Finally, despite their findings on ectopic pregnancies (see above), the authors speak in general terms about “confusion on this issue” and, after finding that “restrictions were uncommon,” they go to on

to encourage leaders of religiously affiliated institutions to inform their physicians regarding which treatments for ectopic pregnancy are prohibited. Confusing.

At the end of 2013, Freedman and Stulberg published an article together in *AJOB Primary Research* (4, no. 4 [2013]: 1-10) titled, “Conflicts in Care for Obstetric Complications in Catholic Hospitals.” The article is based on interviews with 31 ob-gyns from around the country “most of whom work or have worked in Catholic hospitals” (1). Four had not worked in Catholic hospitals, but they are said to have drawn upon their familiarity with Catholic health care ethics as well as their experience accepting transfers from religious hospitals. Five physicians were referred by a colleague in the study, which sounds rather questionable.

These physicians “recounted experiences that demonstrate how Catholic bioethical directives affect their management of complications that can arise during pregnancy. We show how certain treatments can be perceived as morally imperative or neutral and medically necessary care by the ob-gyns interviewed, and as prohibited, illicit acts by Catholic health care authorities” (1). They go on to explain: “In particular, we focus on physicians’ and hospital authorities’ ...conflicting beliefs about care for cases in which patients were already losing a desired pregnancy, the patient’s health was at risk, and/or the fetus would never be viable, and treatment to facilitate the end of the pregnancy represented the standard



in non-Catholic settings” (1). While a number of the authors’ specific explanations (especially of Catholic health care ethics), interpretations, and inferences could be challenged, I will instead make a few general observations:

- The authors leave the reader with the impression that the situations described by the physicians and in the article are typical of how obstetric complications are handled in all of Catholic health care. This is extremely problematic for a number of reasons. First, the authors’ findings are based on interviews with only 31 ob-gyns, four of whom had not actually worked in Catholic health care and five of whom were recommended for inclusion in the study by colleagues who were already in the study. How representative is this of the experience of 1,500 or more ob-gyns practicing in Catholic hospitals? Second, there is no consideration given to how often these situations occurred. Were they isolated instances? Was there a recurrent pattern? This is very significant. Third, there is no context for the authors’ discussion, that is, the authors focus on those instances of treatment for obstetric complications that supposedly went wrong, but how do those

numbers compare to successful treatment of obstetric complications? If treatment is inappropriate or inadequate in a majority of cases, that is one thing. But if it is appropriate in the vast majority of cases, that is another, and it tells a different story. This information is also critical for a fair assessment of the treatment of obstetric complications in Catholic hospitals. Fourth, we don’t know anything about outcomes. Were patients harmed? This after all is the bottom line. There may be somewhat different approaches to some very few obstetric complications in Catholic hospitals, but what is the impact of this on the well-being of mother and fetus?

Two final thoughts. These and other articles and reports have chosen to disparage Catholic health care and Catholic health care’s treatment of and care for women with difficult pregnancies on the basis of very limited information and questionable methodologies. They have also chosen not to consider the tens of thousands of women every year who receive excellent prenatal care and who successfully deliver in Catholic hospitals with high degrees of satisfaction. They have chosen not to consider the vast majority of complicated pregnancies that have been successfully treated to the satisfaction of all those involved. And they have chosen not to take into account the

large numbers of ob-gyns practicing in Catholic hospitals who have not had conflicts with administrators and ethics committees over the *Ethical and Religious Directives*. And yet they are willing to call into question the competency of Catholic hospitals, especially in obstetrics and gynecology, and their role in U. S. health care.

Freedman and Stulberg make several suggestions toward the end of their article that are reasonable and that should be taken seriously. The authors write: “[P]atients should have a right to know about how care for obstetric emergencies may be different in Catholic versus non-Catholic hospitals before selecting a

Catholic provider for obstetric care. Furthermore, physicians should look carefully into the Directives (and other hospital ethics policies) and how they’re applied before accepting a job or applying for staff privileges. And ... ethics committees should communicate as clearly as possible with physicians about what is and what is not allowed, to avoid confusion in emergencies. This may help those involved understand and anticipate conflicts, and may even allow physicians and patients to avoid crises before they arise” (9). Not bad advice.

R.H.

## Of Note

### **Ethical Issues as Scientists Peek into Baby Genes**

The National Institutes of Health announced a five-year pilot project to look at the ethical and practical questions of infant genome sequencing. In each of the four cities chosen, researchers will be studying different applications of the technology. At Children's Mercy Hospital in Kansas City, gene mapping will be used to diagnose newborns in the intensive care unit. At the University of California in San Francisco, the new technology will look for genes involved with immune disorders. At the Brigham and Women's Hospital in Boston and the University of North Carolina in Chapel Hill, the study will focus on healthy infants and observe what information parents want to know about their children. Dr. Jonathan Berg, lead researcher at UNC, cautioned, "we aren't even sure that genome-scale sequencing in newborns is really a good idea." He suggests that instead of a one-time genetic mapping, "we will use targeted sequencing at certain times in a person's life, when that specific information will actually be medically useful." (Lauran Neergaard, *The Associated Press*, Oct. 7, 2013).

### **Costliest One Percent of Patients Account for 21 Percent of U.S. Health Spending**

A recent report by the federal Agency for Healthcare Research and Quality found

that in 2010 five percent of patients accounted for 50 percent of all health care spending while the bottom 50 percent of patients account for only 2.8 percent of spending. The five percent, high-frequency patients, often suffer from heart failure, kidney disease, or diabetes together with psychiatric complications. A new phenomenon called "extreme uncoordinated care" contributes to these high-cost patients. The phenomenon refers to patients who use hospitals, out of habit or lack of knowledge, for care that can be achieved more cheaply and effectively through outpatient options. To lower costs and avoid readmission penalties under the Affordable Care Act, hospitals and insurance companies are developing coordinated care plans. One such program, the University of Michigan's Complex Care Management Program, assigns case managers to follow patients after discharge. The case managers assist the patients in getting to doctor appointments, obtaining medication, and utilizing other community resources. This program decreased annual spending by \$2,500 per patient. Another such program, Health Connect sponsored by Medical Mall Health Services, conducted similar activities, consultation before discharge, follow up calls and visits by nurses, and found similar results. Readmission to the hospital within 30 days of discharge dropped 34 percent. (Sandra G Boodman, *Kaiser Health News*, Oct. 8, 2013).

## Growing Up Poor Changes Young Brains

A recent study published in *JAMA Pediatrics* found that poverty in childhood affects brain structures later in life. The study conducted by Joan Luby, MD and colleagues at Washington University School of Medicine in St. Louis, reported that impoverished children have smaller white and gray matter and hippocampus and amygdala volume. The researchers did observe that parental support positively influenced left and right hippocampus volumes. In an editorial on the study, Charles A. Nelson of Boston Children's Hospital concluded, "Exposure to early life adversity should be considered no less toxic than exposure to lead, alcohol, or cocaine, and, as such, it merits similar attention from the public health authorities." (Christ Kaiser, [www.medpagetoday.com/Pediatrics/Paren-ting/42536](http://www.medpagetoday.com/Pediatrics/Paren-ting/42536), Oct. 28, 2013).

## Health Staffs Get Flu Shots to Avoid Penalty

Reporting flu vaccination rates among health-care workers is mandatory under a Centers for Medicare and Medicaid Services quality reporting program. Failure to report leads to penalties that would reduce payments. By 2020, the federal government wants the vaccination rate of health-care workers to be 90 percent. Some states require health-care workers to get the flu shot or sign a declaration stating their refusal. Some hospitals require the vaccination while others give the workers a choice: either

receive the vaccine or wear a mask. Karen Higgins, co-president of National Nurses United, said that while the union encourages vaccination it does not support mandatory vaccination. She also argues that the alternative of wearing a mask is not only difficult to do all day but appears to "brand" or shame workers who are not vaccinated. (Laura Landro, *The Wall Street Journal*, Oct. 31, 2013).

## We're No. 26! U.S. Below Average on Most Health Measures

A new report by the Organization for Economic Cooperation and Development (OECD) found that the United States spends more money on health care but Americans have a shorter life expectancy than the average. The annual survey compares 34 member countries on a spectrum of health related topics. The United States has excellent care for stroke and cancer patients but also has high rates of diabetes and heart disease related deaths. The U.S. infant mortality rate is 6.1 deaths for every 1,000 live births ranking it near the bottom and well below the OECD average of 4 deaths per 1,000. The survey also found that Americans have the highest rate of obesity at 36.5 percent. Americans have high rates of MRI exams (103 per 1,000 people), CT exams (274 per 1,000 people) and spends more on drugs (\$985 a year per person on average). (Maggie Fox, NBC News, Nov. 21, 2013).

### **\$50M Awarded Over Birth Defect; Test Said Baby Would Be OK**

Brock and Rhea Wuth had a 50-50 chance of having a child with a rare genetic defect called an “unbalanced chromosome translocation.” The lab results they received stated that their child would not have the defect. When their son, Oliver, was born it was found that he did have the rare genetic defect. Brock and Rhea Wuth filed a wrongful-birth case because if they had known about the defect they would have ended the pregnancy. In King County, Washington, the Supreme Court jury placed blame, equally, on the Valley Medical Center in Renton and Laboratory Corporation of America (LapCorp) in the amount of \$50 million. The Valley Medical Center did order the lab test but failed to send Lap Corp the additional information to test for the rare genetic disorder. LabCorp failed to follow procedure when it did not make a follow-up phone call to the Valley Medical Center. (Carol M Ostrom, *The Seattle Times*, Dec. 11, 2013).

*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 Courtney E. Thiele, (J.D. anticipated 2014) and Srishti Miglani (J.D./M.P.H. anticipated 2015).*

### **Medicaid Growth Could Aggravate Doctor Shortage**

In the 26 states expanding Medicaid, millions of Americans will be added to the Medicaid program, thereby burdening the existing shortage of doctors, mainly specialists, serving the Medicaid population. In addition, even in states not expanding Medicaid, many patients who were previously eligible but had not enrolled in Medicaid, are also predicted to add to the enrollment. Even though community clinics and managed care companies have hired more medical staff members and health professionals, this increase still might not be enough to meet the demand that will be created by the Medicaid expansion population. The low reimbursement rates have historically driven away doctors from serving Medicaid beneficiaries. The Affordable Care Act increases the Medicaid reimbursement rate for primary care doctors until the end of 2014, and this increase brings the Medicaid payment rates to the same level as Medicare. However, with the states’ slow implementation of this temporary payment increase, there is still an insufficient number of doctors accepting Medicaid patients. (Abby Goodnough, “Medicaid Growth Could Aggravate Doctor Shortage,” *The New York Times*, (Nov. 28, 2013), <http://www.nytimes.com/2013/11/29/us/ack-of-doctors-may-worsen-as-millions-join-medicaid-rolls.html>).

## Obama Administration Relaxes Rules of Health Care Law Four Days Before Deadline

One of the major promises made by President Obama regarding the Affordable Care Act (ACA) was that people who liked their existing health insurance plans will be able to keep them. However, that promise was broken when health insurance plans for several million people were canceled because the plans did not meet the new ACA benefit standards. In order to calm the public and political outrage over these canceled plans, the Department of Health and Human Services amended the rule, thereby allowing people with canceled health plans to either buy a bare-bones, catastrophic plan or claim a hardship exemption if the plans sold through the exchange were not affordable. Insurance companies did not welcome this change. The health insurance industry is concerned that this change is a step back for the ACA's goal to promote "affordable and comprehensive coverage on a widespread basis." Another fear facing the industry is that healthy people whose plans were canceled will claim the hardship exemption and not sign up for health insurance until they need it, which will create an imbalance in the insurance pool with more sick than healthy people. However, federal health officials do not think that many healthy people will opt for the exemption and will instead continue to be insured. (Amy Goldstein, "Obama Administration Relaxes Rules of Health-Care Law Four Days Before Deadline," *Washington Post*, (Dec. 19, 2013).

<http://www.washingtonpost.com/national/health-science/obama-administration-relaxes-rules-of-health-care-law-four-days-before-deadline/2013/12/19/81bc3132-690b-11e3-8b5b>

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## U.S. Doctors Warn Congress Cutting Food Stamps Could Mean Higher Medical Bills

As Congress prepares to come to a compromise—which will certainly include food stamp cuts—on the Farm Bill, doctors warn legislators of the detrimental health effects, mainly hunger, of such cuts. Over time, hunger can lead to increased rate of diabetes and developmental problems in young children. According to Dr. Thomas McInerney, past president of the American Academy of Pediatrics, poor families buy "cheap, high-calorie junk food" to satiate their hunger but that food does not provide them with proper nutrients. This can lead to later-in-life diabetes, or iron deficiency which could have a significant effect on the developing brain of a young child. According to the Agriculture Department, a family of four receives an average household benefit of only \$270 per month. The Supplemental Nutrition Assistance Program (SNAP) currently costs \$80 billion per year, but cutting food stamps could result in higher

medical costs under Medicare and Medicaid. A recent study conducted by the Robert Wood Johnson Foundation and the Pew Charitable Trusts, showed that a reduction of \$2 billion in food stamps could lead to an increase of \$15 billion in medical costs for diabetes over the next 10 years. However, proponents of cutting the food stamp program are fixated on the spiraling costs of the SNAP program. (“U.S. Doctors Warn Congress Cutting Food Stamps Could Mean Higher Medical Bills,” *The Guardian*, (Jan. 10, 2014, 11:16 PM), <http://www.theguardian.com/world/2014/jan/10/doctors-warn-congress-food-stamps-cuts-higher-bills>).

### **Surgeon General Report Links More Disease, Health Problems to Tobacco Smoking**

A new report issued by the Surgeon General shows even more diseases and health problems are now linked to the smoking of tobacco products than the commonly known risks of heart disease and lung cancer, determined to be linked to smoking cigarettes fifty years ago. These additional risks from smoking include developing the following: “Type 2 diabetes mellitus, age-related macular degeneration, erectile dysfunction and rheumatoid arthritis ... impair[ing] the immune system, worsen[ing] asthma and caus[ing] cleft lips and palates in fetuses.” There were also risks from exposure to secondhand smoke, including causing strokes. The Surgeon General’s report was the most recent in a series of 30 reports issued regarding the hazards of

smoking since 1964. In addition to the new risks found to be associated with smoking, this report found that the risk of developing lung cancer from smoking is much higher now than in 1964. The report attributes the likely cause to be changes in the design and composition of cigarettes. Despite the public health efforts resulting in a significant decline cigarette smoking in the United States (from 42% of adults in 1964 to 18% of adults in 2012), the CDC still reports that “443,000 Americans die each year” from cigarette smoking, indicating the need to continue the fight against smoking and the diseases it causes.

(Brady Dennis , Surgeon General Report Links More Disease, Health Problems to Tobacco Smoking, [http://www.washingtonpost.com/national/health-science/surgeon-general-report-links-more-diseases-health-problems-to-smoking-tobacco/2014/01/16/c0552c90-7eb5-11e3-95c6-0a7aa80874bc\\_story.html](http://www.washingtonpost.com/national/health-science/surgeon-general-report-links-more-diseases-health-problems-to-smoking-tobacco/2014/01/16/c0552c90-7eb5-11e3-95c6-0a7aa80874bc_story.html)).

### **To Schedule a Doc Visit, Get in Line**

A shortage of physicians is resulting in exorbitant wait times to see a doctor. In a survey of 15 metropolitan areas, including Boston, where wait times were longest, and Dallas, where wait times were shortest, the average wait time for new patients to see a physician is 18.5 days. The range varied by city and specialty. Despite these long waits, the survey actually showed a decline in wait times since 2009 when wait times averaged 20.9 days. However, with additional people gaining health care coverage under the

Affordable Care Act, the wait times may increase again. If physicians are not accepting Medicaid and certain insurance plans, the increased wait time will transfer to the emergency room departments. Despite the likely increase in volume, Ken Hertz of the MGMA Health Care Consulting Group, points out that volume is not the only factor to consider in managing wait times, and that effective scheduling and operating systems in place play a significant part. Mr. Hertz concludes, “The successful practices will figure out new ways and approaches to shortening wait times. This isn’t going to be acceptable.” (Jenny Gold, To Schedule a Doc Visit, Get in Line, <http://capsules.kaiserhealthnews.org/index.php/2014/01/to-schedule-a-doc-visit-get-in-line>).



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(Prepared by CHA intern, Lori Ashmore-  
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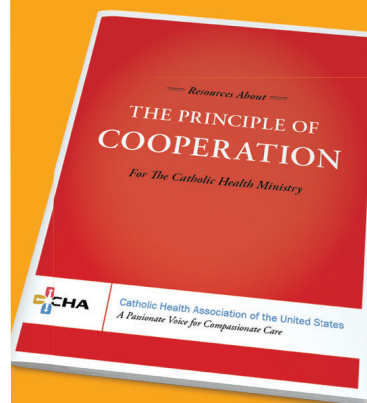
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