

PERINATAL PALLIATIVE CARE

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Incompatible with Life: A Fictional Case Narrative

“Incompatible with life.”

Dr. Hansen’s last three words hung in the air like toxic, heavy smog, making it difficult for me to breathe. I glanced over at Marcus to see if perhaps I had misunderstood the phrase. No luck; my husband also had a look of desperate confusion spreading over his face. I hadn’t heard wrong. But how could it be possible? My baby was very much alive, and she proved the fact by delivering a sharp poke to my ribs right then and there. How could there be something so desperately wrong that she could be considered incompatible with life? I understood what Dr. Hansen had explained about a broken brain, heart, and intestines—but I could not apply those ideas to the active little person inside of me. It couldn’t be possible.

“I know this is very hard to hear, Mr. and Mrs. James, but we are going to have to make some important decisions very soon. Your pregnancy is already at 18 weeks, so we only have three weeks before it would become difficult to terminate. I understand that you will need some time to process this in private, but can we set a follow up-appointment for a week from now?”

“Terminate? You mean abortion, right?” Marcus spoke the words that had become stuck in my throat.

“Yes, technically, it would be an abortion,” the words sounded cold and harsh but I forced myself to pay attention. “But in these cases we generally consider it to be an extremely premature induced delivery. It would mean that you would not have to prolong the inevitable if you did not want to. You could think of it as turning off the life support for someone who is terminally ill and allowing nature to take its course.”

“And if we decide to continue the pregnancy?” Marcus’ voice shook a little as he continued this surreal conversation. I was always amazed at the calm way my husband could handle difficult situations, but this seemed to be taking a toll on his confidence as well. “Is there any danger for Kate if we decide to continue?”

“No more danger than any typical pregnancy and delivery. There are always risks with pregnancy . . . there’s eclampsia, DIC, uterine hemorrhage—rare things, but not outside of the scope of possibility. That is one of the reasons why many parents in your situation choose to end their pregnancy early. There is no reason for you to suffer by prolonging the inevitable. Now, as I said, I want to give you two some time to think about all of this, but we will have to move pretty quickly. Can we make an appointment for next week?” Dr. Hansen leaned back in the squeaky chair and folded his white-clad arms across his lap.

I found myself nodding numbly, then somehow the next thing I was aware of was Marcus opening the door of our car and leading me across the front porch. “I’d better call your mom and dad,” he said quietly, setting me down on our porch swing. Oh yeah, mom and dad—they were probably close to bursting, waiting to hear the news about their grandchild’s gender. This morning as I prepared for my ultrasound, I thought that would be the most important news of the day. Boy, was I wrong. What were we going to do now? I wrapped my arms around my swelling middle and let the tears begin to flow as I slowly rocked on the porch swing.

Approaches to Unfavorable Prenatal Diagnosis

Modern pregnancies are often publicly celebrated in a blur of Instagram-perfect gender reveals and monthly chronicles of growing baby bumps. In light of all of the “pregnancy publicity,” it is sometimes hard to remember that sometimes a pregnancy is not picture-perfect. It is interesting that this culture that celebrates and publicizes wanted pregnancies is also a culture that celebrates the “right” to abortion-on-demand. Abortion is seen as a safe and simple solution to the uncomfortable situation of unwanted pregnancy and as a solution to the painful problem of an unfavorable prenatal diagnosis. With the advent of a myriad of prenatal diagnostic testing options, from alpha-fetoprotein screening to 4D ultrasounds, there is an increased potential that a serious anomaly will be discovered prenatally. In this situation, even parents who would describe themselves as pro-life might feel as if termination of the pregnancy is the best option for themselves and their child. There is, however, an alternative model for supporting families through the journey of pregnancy and parenting a baby with a serious anomaly. This model is



from the director's desk

BY PAIGE C. CUNNINGHAM, JD, PHD (CAND.)
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Several months ago, Mike Cospser wrote a commentary on “The Banality of Abortion.”¹ His reminder of Hannah Arendt’s observations about the trial of Adolf Eichmann, the Nazi S.S. officer who coordinated transportation of millions of people to death camps in Europe, is profoundly prescient. In *The Origins of Totalitarianism*, Arendt, who escaped the terror of the Third Reich, struggled to describe the bland face of evil she confronted in the courtroom.

Evil wore the face of a bureaucrat, of someone who fervently believed that he was creating a better world. He was not a maniacal bloodthirsty villain, but a respectable citizen who conformed to the social realities and political expectations of his day.

We tend to look smugly at the past, claiming moral superiority over those who are now historical pariahs. But is present reality all that different?

In late June, the U.S. Supreme Court decided that state regulations designed to protect a woman’s health interfere with her constitutional rights and are unconstitutional. Why? Because the regulations in question affect free-standing abortion centers and abortionists, and the right in question is “a woman’s right to decide to have an abortion.”² Abortionists were required to have admitting privileges at a nearby hospital, and the clinic had to meet the minimum standards for all other ambulatory surgical centers. Some clinics might close, limiting convenient access to abortion, the Court speculated, and thus the regulations unduly burden a woman’s constitutional right to choose abortion.

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Five members of our highest judicial authority, with unreviewable powers, decided that the Texas law evinced a “virtual absence of any health benefit.”³ Further, it declined to follow the explicit language of “what must surely be the most emphatic severability clause ever written.”⁴ The Court could not be bothered to make the effort of striking down only the objectionable provisions,⁵ instead holding that the following regulations, among others, are unconstitutional:

- Surgical center patients must “be treated with respect, consideration, and dignity.”⁶
- Patients may not be given misleading “advertising regarding the competence and/or capabilities of the organization.”⁷
- Centers must maintain fire alarm and emergency communications systems, and eliminate “[h]azards that might lead to slipping, falling, electrical shock, burns, poisoning, or other trauma.”⁸
- Each center “shall develop, implement[,] and maintain an effective, ongoing, organization-wide, data driven patient safety program.”⁹

In its determined effort to preserve unimpeded access to abortion, the Court rejected the cardinal rule of *res judicata*,¹⁰ ignored evidence submitted by the abortion clinics, and revised its standard of review—yet again. As Justice Alito wrote in strong dissent, “in this abortion case, ordinary rules of law—and fairness—are suspended.”¹¹ Once again, abortion distortion is at work.

The law did not prohibit any abortions. The subject of abortion—the unborn child—and the object of abortion—ensuring that child’s death—were never hinted at in the decision. The majority were unhappy that a woman might not have easy access to . . . just what, exactly? Breast cancer treatment centers? Voting booths? Teeth whitening salons? The majority’s carefully sanitized discussion scrupulously avoids any mention of who is being aborted, or what abortion intends.

The Court was equally dismissive of the genuine grounds state legislatures have for regulating abortion centers: preventing another “Kermit Gosnell scandal.” While admitting that women died at his hands, that unlicensed staff did abortions, that his facility was filthy, and a host of other problems, the majority observed that wrongdoers like him “are unlikely to be convinced to adopt safe practices by a new overlay of regulations.”¹²

The Center for Bioethics & Human Dignity (CBHD) is a Christian bioethics research center at Trinity International University.

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In the Spring 2016 issue of *Dignitas*, I wrote about the investigation into the harvesting of fetal body parts after abortion. This practice, too, is clothed in the language of regulations and medical jargon, obscuring the sine qua non for this practice: a steady supply of aborted fetuses. As long as regulations are followed, one need not consider the moral ramifications of medical research that exploits the deaths of nonconsenting, very early human beings. After all, what reasonable and compassionate person could disagree with finding cures for serious diseases?

Recent evidence obtained by the House Select Investigative Panel manifest a callousness toward the recently deceased. One lab notebook celebrates efficiency—“One entire retina!”—and notes that fetal brains are being sold for use at a summer camp.¹³ I wonder, will the campers be disturbed? Or will this be just another “cool” thing?

While I have no grounds to assess the moral probity of all those who approve, defend, participate in, or exploit the fruits of the practice of legal abortion in the U.S., I do question the ease with which they justify their particular role. Whether they are a judge, medical researcher, abortionist, or tissue procurement organization, they all seem to claim nobility of purpose, while papering over the lethal exploitation of unborn human children and the mothers who carry them. Perhaps Hannah Arendt’s observations are chillingly contemporary, and that in the pursuit of “a better world,” these “respectable citizens” are conforming to the social realities and political expectations of their day. ●●●

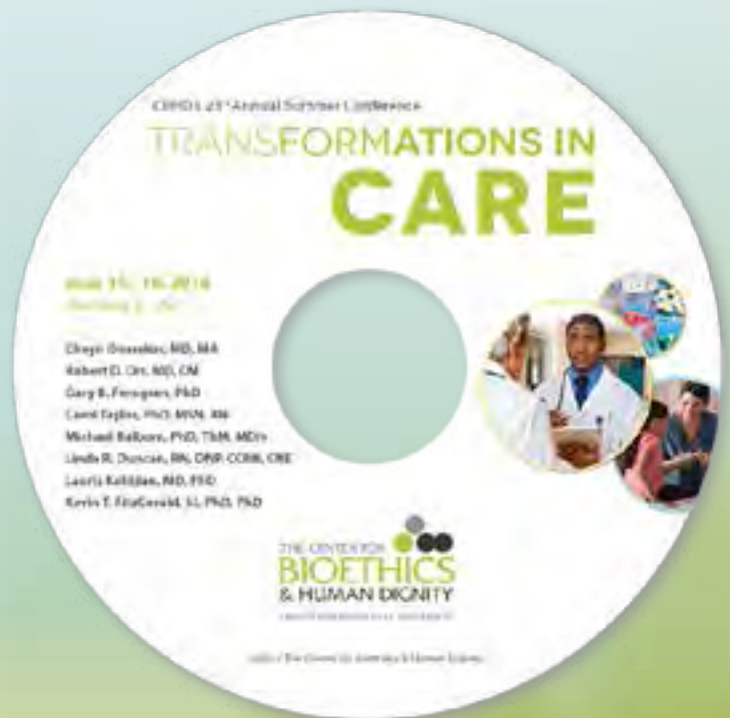
- 1 Mike Cospser, “The Banality of Abortion.” The Ethics & Religious Liberty Commission, January 6, 2016, <http://erlc.com/resource-library/articles/the-banality-of-abortion> (accessed July 21, 2016).
- 2 *Whole Woman’s Health v. Hellerstedt*, 579 U.S. ____ (2016), slip op. at 1.
- 3 *Id.*, slip op. at 26.
- 4 *Id.*, slip op. at 2 (Alito, J., dissenting).
- 5 “Federal courts have no authority to carpet-bomb state laws, knocking out provisions that are perfectly consistent with federal law, just because it would be too much bother to separate them from unconstitutional provisions.” *Id.*, slip op. at 40 (Alito, J. dissenting).
- 6 Tex. Admin. Code, tit. 25, §135.5(a).
- 7 §135.5(g).
- 8 §§135.41(d), 135.42(e) and §135.10(b).
- 9 §135.27(b).
- 10 Namely, claim preclusion, meaning that previously decided matters may not be re-litigated.
- 11 *Whole Woman’s Health*, slip op. at 19 (Alito, J., dissenting).
- 12 *Id.*, slip op. at 27.
- 13 Criminal Referral Letter to the Attorney General of New Mexico from Marsha Blackburn, Chairman of the U.S. House of Representatives, Committee on Energy and Commerce Select Investigative Panel. The Energy and Commerce Committee, June 23, 2016, <https://energycommerce.house.gov/sites/republicans.energycommerce.house.gov/files/documents/114/letters/unm-referral.pdf> (accessed July 21, 2016).

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known as perinatal palliative care (PPC).

Using abortion as a solution for unfavorable prenatal diagnosis only serves to compound a difficult situation through the logic that inducing death prematurely is a way to circumvent pain and grief. The beauty of PPC is that it provides a way to celebrate life, even when that life may be very short.

Termination of Pregnancy for Fetal Anomalies

Why do obstetricians often recommend termination of pregnancy for fetal anomalies (TOP-FA)? One reason often given for TOP-FA is that it can prevent a baby with severe anomalies from suffering through birth and a painful natural death.¹ In this way, TOP-FA is presented as the most loving choice that parents can make for their unborn fetus. No parent wants to see their child suffer unnecessarily. However, this perspective fails to take into account the pain that an unborn child may suffer through an abortion procedure. Just because an individual cannot communicate regarding their pain does not mean that they are not experiencing pain. So, depending upon the type of procedure employed and whether anesthesia is administered to the unborn child, the use of abortion to truncate a child's life of suffering may actually inflict more pain and distress on that child.

Another reason given for TOP-FA is that it can stop parents' emotional pain and suffering, bring closure, and allow them to start the healing process.² Well-meaning medical professionals may often tell parents “that they should terminate the pregnancy and ‘start again.’”³ There is no doubt that a pregnancy complicated by fetal anomaly is a tragic and heart-breaking situation for parents, but does it follow that termination of that pregnancy is the best route to a family's emotional healing from that tragedy?

A study of women in the Netherlands found that “termination of pregnancy because of fetal anomaly . . . may cause sustained psychological morbidity.”⁴ The study identified feelings of grief and

guilt in women, and found that 17.3% of the participants even showed pathological scores for post-traumatic stress 2–7 years after their pregnancy termination. Another study compared women who

Using abortion as a solution for unfavorable prenatal diagnosis only serves to compound a difficult situation through the logic that inducing death prematurely is a way to circumvent pain and grief.

experienced TOP-FA with women who experienced the premature birth of their baby. This study found that the women who had undergone TOP-FA had a higher incidence of psychiatric disorders than the women in the comparably high-stress situation of premature birth.⁵ Terminating an emotionally difficult pregnancy is not a shortcut through the grieving process. Unfortunately, the experience of fathers who experienced the loss of their child due to TOP-FA has not been adequately studied, but it is safe to assume that fathers also are likely to experience serious emotional distress related to this traumatic event.

Termination may also be encouraged because it is the easiest option for the healthcare team, since families who choose to continue their pregnancy in spite of poor prenatal diagnosis require much more support than those with typically developing pregnancies.⁶ A study of the experiences of women who received a diagnosis of fetal malformations found that “most of the women who expected a baby with an abnormality experienced the information given as insufficient, often misleading, conflicting, or incoherent, and sometimes negative.”⁷ Other research has found that in instances of bad news during prenatal care “physicians receive little or no training in communicating bad news, and they generally feel quite uncomfortable about doing so.”⁸ Caring for a maternal-fetal dyad in the setting of an unfavorable prenatal diagnosis can undoubtedly be a difficult

emotional experience for healthcare professionals as well. It is likely that sometimes parents are counseled toward TOP-FA because the healthcare team does not feel that it has adequate knowledge or

resources to support families through this challenging experience.

When termination is presented as the only option, parents may not feel that they would have much support to help them through the remainder of their pregnancy, if they chose to continue it. Kevin McGovern notes,

In these circumstances, a health professional may also press the parent(s) to agree almost immediately to the termination, even though the parents really cannot think clearly because they have just been told devastating news about their unborn child. Other times, the option of continuing the pregnancy is mentioned, but it is presented as an inferior option which would only appeal to people who are themselves deficient in some way. For example, terminating the pregnancy might be presented as decisive action to end a nightmare, whereas continuing the pregnancy could be presented as the only option for those who are incapable of decisive action.⁹

When serious fetal anomalies are discovered, it is often during a routine ultrasound performed at 16–20 weeks of pregnancy. Because of this, healthcare professionals may feel pressure to have their patient make a quick decision about termination, as many states have laws which restrict abortion after 20 weeks.

The healthcare team's ethical responsibility to the child is to treat her with respect and dignity in its life and potential death. Just because this person may



only experience life from the inside of its mother's womb does not make the child's life worthless. The model of perinatal palliative care recognizes this, and seeks to maximize the potential of the infant's life.¹⁰

Perinatal Palliative Care as an Alternative to Termination of Pregnancy

The World Health Organization defines palliative care as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”¹¹ Palliative care differs from hospice in that palliation is appropriate even at the beginning of an illness and is compatible with life-extending treatments. (The title of perinatal palliative care is preferred in this paper, but some of the literature referenced may refer to the same type of program as “perinatal hospice.”)

The hallmark of palliative care is its

interdisciplinary approach and its goal of enhancing the patient's (and family's) quality of life. The palliative team takes a holistic approach to caring for the patient and their family, including other disciplines such as social work and chaplaincy in the interdisciplinary team. Palliative care is life-affirming while, at the same time, considering death to be a natural process.¹² In the perinatal and neonatal setting, “palliative care is an entire milieu of care to prevent and relieve infant suffering and improve the conditions of the infant's living and dying. It is a team approach to relieving the physical, psy-

“Palliative care is life-affirming while, at the same time, considering death to be a natural process.”

chological, social, emotional, and spiritual suffering of the dying infant and the family.”¹³

Palliative care can be seen as expert symptom-directed care, with all of the energies of the healthcare team devoted to reducing suffering. This concept is supported by leading organizations

driving the practice of high-quality neonatal care. The National Association of Neonatal Nurses' (NANN) Position Statement on Palliative and End-of-Life Care for Newborns and Infants states that “palliative care orders to manage discomfort, pain, and other distressing symptoms . . . [should use] the least invasive effective route of delivery available” and that “comfort measures such as holding and kangaroo care” (skin-to-skin contact with parents) should be encouraged. NANN also recommends “ongoing assessment of pain and sedation with a validated instrument” and “discontin-

uation of painful assessments.” All of these interventions are performed with the ultimate goal of maximum comfort for the infant. NANN even goes so far as to recommend that “if the family is not available, nurses or other care providers should hold and comfort the infant.”¹⁴

Once the infant is born, the PPC team

has the ethical obligation to assure that the infant’s basic needs for comfort are met. This may include basic fluids and nutrition, warmth, oxygen delivered via nasal cannula or “blow by” (invasive methods of ventilation are generally considered inappropriate in palliative care), pain control, skin care, and maximal parental contact.¹⁵ In a PPC model, care is never withdrawn or withheld. Care is an ongoing act that continues before the child is born, and even after the child dies. However, the focus of care in a PPC model is comfort and not healing.

During the pregnancy, birth, and life of a child with severe anomalies, it is ethically appropriate to forgo intensive care measures to prolong their life, if those measures are deemed futile or the parents decline these measures. The goal of palliative care is to provide the most peaceful life and death as possible. To this end, all interventions should be performed with this goal in mind. Often, infants with severe anomalies may not be able to eat by mouth. The parents and palliative care team should discuss the appropriateness of artificially administered nutrition and hydration (ANH) before the infant’s birth. Since every case is different, the appropriateness of different methods of ANH may vary between cases. The refusal of ANH might also be appropriate since refusing food and drink are considered to be a natural part of the dying process and can actually increase the dying child’s comfort.¹⁶

A palliative care model also provides parents with the ability to participate in comforting their child through painful procedures and any discomfort associated with the dying process. If a parent’s goal is to reduce pain and suffering for their child, members of the perinatal palliative care team will help ensure that goal is met. Terminating the pregnancy does not give parents that option.

Another benefit for parents who choose PPC is that they can be given control over many aspects of the birth, life, and death of their child. Customized birth plans can include provisions like forgoing fetal heart rate monitoring or allowing

a grandmother to help with the infant’s bath. PPC also provides flexibility in situations where the exact prognosis of a child’s life is unknown. It leaves the door open for more intensive care to be provided if the infant is more vigorous than expected, while still allowing for the possibilities of the “worst-case scenario.” One of the most important aspects of PPC is creating these advance-directive-type plans for care. Knowing what to expect can be empowering to parents as

and friends, who otherwise may dismiss a terminally ill but unseen baby as simply a forgettable accident of nature.¹⁸

With PPC, parents can take the remainder of their pregnancy to create special memories with their unborn child by, for example, taking pictures, playing music, “meeting” grandparents, or even taking their child with them on a trip. PPC should not stop any routine care from occurring (such as ultrasound scans), but

“Having a PPC plan in place can free parents to savor precious moments with their child instead of having to make difficult decisions in the spur of the moment.”

they anticipate this difficult and painful experience. “Without a plan, parents are often forced to make difficult decisions in the moment, when they are sleep-deprived and emotionally spent.”¹⁷ Having a PPC plan in place can free parents to savor precious moments with their child instead of having to make difficult decisions in the spur of the moment. Decisions about whether to attempt resuscitation or administer artificial nutrition and hydration can be made outside of the pressure of the hospital setting.

In addition, a PPC model provides families with the time to be able to begin a healthy grieving process by making plans for their child’s birth, life, and death. Some parents express that they see continuing their pregnancy as a way to give their child as long and happy a life as possible. Amy Kubelbeck, whose son Gabriel was diagnosed with a lethal heart anomaly at 25 weeks gestation, puts it this way:

There is no shortcut through grief, as much as contemporary society would wish there to be. Parents who continue their pregnancy receive the gift of time for anticipatory grief, and they can find solace in the knowledge that they protected their baby and gave their baby—and themselves—the gift of a peaceful, natural death. And parents may receive greater understanding and support from family

instead maximize parent’s opportunities to experience their child who may only be alive through the pregnancy and perhaps a short time after birth.

The responsibility of supporting the goals of PPC lies with every member of the perinatal care team, but nurses often find themselves in the unique position of spending a great amount of time with their patients and their families. Because of this, “the ultimate success of perinatal hospice depends on the patience, sensitivity, and sense of interdependence of nurses at the bedside, as well as their willingness to facilitate the mourning process.”¹⁹ Nurses are often responsible to explain to parents what they should expect throughout the labor and delivery process. A special prenatal class can be set up for a PPC case, so that the parents can learn about labor and delivery with special attention to the different concerns that they are sure to have. At delivery, nurses can help the family make special memories of their child such as taking pictures or taking handprints and footprints. Nurses should direct parents towards comforting and caring tasks they can perform for their baby.²⁰ When the infant’s death is imminent, the nurse can help prepare the family for what they might expect to see. Also important is the role of the nurse in assessing the infant

and assuring that their comfort and dignity are respected. If the infant is expected to live long enough for discharge from the hospital, sometimes the goals of palliation might require nurses to think outside of the box when helping parents develop ways for caring for their child at home. After discharge, a nurse may perform intermittent visits to monitor the infant's status and assure that the goals of the palliative care plan are being met. In all of these stages of care, nurses must be flexible, compassionate, and creative.²¹

PPC has benefits for the whole healthcare team. Anticipatory planning can help healthcare professionals prepare for a situation that might be emotionally difficult for them. Also, having advance directives in place assures that the team will not be required to perform potentially inappropriate interventions on a critically ill neonate. Having a palliative care plan can also potentially be financially prudent, since it can streamline services, and ensure that unnecessary interventions are not performed.²² Since PPC is a relatively new concept, these benefits to the healthcare team have not yet been well studied, but the benefits have been evident in other pediatric palliative care services.²³

The Ethical Background for PPC

A recent proposal has been made in Great Britain that parents of fetuses with severe defects should be encouraged to carry their pregnancies to term for the sole purpose of harvesting the baby's organs once they are born.²⁴ This strictly utilitarian reason for continuing a pregnancy is problematic because it can cause these disabled babies and the mothers who are carrying them to be seen as a commodity. This is further complicated because declaring brain death is usually the trigger for the harvesting of organs, but regarding infants, "Brain death as the irreversible and permanent loss of cerebral and brainstem function, is relatively uncommon among newborns who need life support."²⁵ This means that infants are not generally considered good organ donor candidates, since they are not often declared "brain dead" while on life

support. It is chilling to consider that persons who cannot be declared dead would be subject to organ harvesting. Although parents may wish to explore the possibility of donating some tissues such as umbilical cord blood, they ought not to be counseled to continue their pregnancy only to provide tissues or organs for donation. There are many other important reasons to provide parents with the options and support to continue a pregnancy instead of terminating after the diagnosis of fetal abnormalities.

In encouraging parents to terminate the life of a fetus because of its anomalies, the healthcare professional is making some important moral and ethical statements. Metaphysically, the underlying assumption behind the suggestion that a fetus with severe anomalies ought to be aborted is that such a fetus does not yet fully possess the rights of personhood. This reasoning seems especially relevant in cases (such as anencephaly) where the infant will never have more than a reflexive awareness of their environment. This assumption relies on the dangerous concept that personhood somehow is defined by a sliding-scale of functionality. To say that a severely disabled fetus is something less than a person begs the question of what level of function an individual must have to be considered a person. Sometimes, the concept of personhood is tied to an individual's potential. It can be argued that since the fetus with severe anomalies lacks the potential to perform the basic functions of life on their own, that they are not fully deserving of the rights of personhood. However, an individual's potentiality is also a sliding scale, with various contributing factors. The concept that a baby is better off dead than disabled does nothing to encourage respect and care for the disabled of our society.

One of the first ethical responsibilities of any healthcare team is to provide their patient(s) with sufficient information for them to make informed decisions regarding their care. This allows them to make truly autonomous decisions. "Encouraging families to make plans for their potentially nonviable infant while

in utero is seen as a type of autonomy for the pregnant patient."²⁶ Information that needs to be provided includes detailed information about the fetal diagnosis, the certainty with which the diagnosis is made (prenatal diagnosis is often not 100% accurate), the potential prognosis and/or course of disease expected, options for the remainder of the pregnancy—including any PPC services available, and general information about community support for ill or disabled infants (if applicable to the case). If the infant is expected to live for a short period of time after birth, parents may want to tour a NICU, or speak with other medical specialists (neonatology, cardiology, GI, or neurology) to learn more about any interventions which may be appropriate for their child. They may want to speak to families who have experienced similar situations, or discuss concerns with their clergy or other counsel.²⁷ The healthcare team ought to support the parents in all of these efforts, so that the parents can make truly informed decisions regarding their pregnancy.

Healthcare professionals are also ethically obligated to not abandon their patients, even if they disagree with the patient's choices. One fear that parents who have experienced a poor prenatal diagnosis often express is that they might be abandoned by their healthcare team, especially if they sense that their primary physician does not support their decision to continue pregnancy. However, the healthcare team should show respect for their patient's decisions, and provide support for them, even if they feel that continuing the pregnancy borders on futility. Even if there is no official PPC team available, these interventions can be performed by any healthcare team.²⁸ As McGovern suggests, parents who choose to continue their pregnancy should be assured that

there is a team of health professionals who will be readily available to them and who have both the professional knowledge and the human compassion to guide them and journey with them through this experience. They must be assured that they will be looked after, and

that their unborn child should not experience pain and suffering as he or she lives through to his or her natural death.²⁹

PPC follows a different model for pregnancy care that appreciates the intense amount of grief that occurs in this type of pregnancy and supports parents in a nonjudgmental way, fully supporting their autonomy.

Conclusion

To find out that an unborn child will die before birth or soon thereafter is devastating news for a family and distressing to the healthcare team. Though their short life might be veiled in heartbreak, even the life of the most disabled infant is significant. Perinatal palliative care provides a solution to an unexpected prenatal diagnosis that affirms life and allows parents to experience a natural grieving process. In the opening narrative, PPC would have given Mr. and Mrs. James, whose fictional story is nonetheless representative of many real life scenarios, a life-affirming alternative.

To some, it may seem a foolish endeavor to spend energy and resources on caring for severely disabled babies who may not even live until birth. However, we are called to provide special care and attention to the most vulnerable members of society. As Christians, we do not have the option of turning a blind eye to the hurting and helpless around us. Throughout Scripture, it is clear that God attributes special value to those who are weak and helpless. In fact, Christ himself stated that “as you did to the one of the least of these ... you did it to me” (Matthew 25:40 ESV), and that “whoever receives one such child in my name receives me, and whoever receives me, receives not me but him who sent me” (Mark 9:37 ESV). How amazing that by lavishing love and care on the weakest of human beings, we are privileged to welcome the God of the Universe himself! Severely disabled babies may not be given much value in our society, but their lives are of infinite importance to God.

Cutting an already short life even shorter

through pregnancy termination may rob us of many important lessons. By caring for someone vulnerable who can never repay us back, we may better learn how to respond to our own weakness and vulnerability, and through tragic circumstances, we may discover a new capacity for love and caring in our communities. As Scripture clearly teaches, “God chose what is foolish in the world to shame the wise; God chose what is weak in the world to shame the strong” (1 Cor 1:27, ESV). When we open our hearts, churches, and clinics to walk the tough road of loving and supporting babies and their parents following an adverse prenatal diagnosis, we can experience a beautiful picture of how much God loves us in spite of our own brokenness. ●●●

- 1 Orlando Women’s Center, “Late Abortion Due to Fetal Anomaly,” http://www.womenscenter.com/late_abortion.html (accessed May 12, 2016).
- 2 Ibid.
- 3 Joan Ramer-Chartsek and Megan V. Thygeson, “A Perinatal Hospice for an Unborn Child with Life-Limiting Condition,” *International Journal of Palliative Nursing* 11, no. 6 (2005): 274.
- 4 M. J. Korenromp et al., “Long-Term Psychological Consequences of Pregnancy Termination for Fetal Abnormality: A Cross Sectional Study,” *Prenatal Diagnosis* 25, (2005): 194.
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DEVELOPMENTS IN THE PRACTICE OF PHYSICIAN-ASSISTED DEATH SINCE ITS LEGALIZATION IN THE NETHERLANDS

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Public prostitution, freely available marijuana, conventional same-sex marriage—yet the Netherlands is, perhaps, best known around the world for pioneering physician-assisted death. Outside of the country, its reputation is easily misconceived and sometimes blown out of proportion. For example, in 2012 the Dutch were astonished to hear this assertion of former U.S. Senator and presidential candidate Rick Santorum:

In the Netherlands, people wear different bracelets if they are elderly. And the bracelet is: “Do not euthanize me.” Because they have voluntary euthanasia in the Netherlands. But half of the people who are euthanized—ten percent of all deaths in the Netherlands—half of those people are euthanized involuntarily at hospitals because they are older and sick. And so, elderly people in the Netherlands don’t go to the hospital. They go to another country, because they are afraid, because of budget purposes, they will not come out of that hospital if they go in there with sickness.¹

His assertions were soon refuted by American journalists.²

A realistic bioethical evaluation of the practice of physician-assisted death in the Netherlands requires deeper analysis of the facts. Such analysis is, unfortunately, not easily accessible, since much

of the data has been published only in Dutch. Therefore, a factual overview of the developments of this practice since its legalization in 2002 is given here.

The History of the Regulation

After a long process of debates and legal cases, the way was opened for legalization of physician-assisted death in the 1980s. In these years, the Royal Dutch Medical Association (hereafter KNMG, the acronym for the association in Dutch *Koninklijke Nederlandsche Maatschappij tot bevordering der Geneeskunst*) negotiated with the Public Prosecutor that physicians would, under certain conditions, not be prosecuted for assisting in death. The Supreme Court also ruled that, despite the prohibition in criminal law, physicians should not be prosecuted under these agreed-upon conditions. The government acknowledged this tolerance in 1994 by establishing a procedure for reporting and reviewing cases of assisted death. It was not until 2002 that the prohibition was legally waived under these conditions. Since then, a physician assisting in death is not punishable if the physician: 1) is convinced that the patient has made a voluntary and well-considered request and that patient’s suffering is unbearable without a prospect of improvement; 2) has informed the patient about his situation and prospects;

3) has come to the conclusion, together with the patient, that no reasonable alternatives exist; 4) has consulted at least one independent physician—who need not necessarily agree with his decision; and 5) terminates the patient’s life with due medical care. Contrary to American states, Dutch law permits not only assisted suicide but also euthanasia—whereby a physician administers a lethal drug to the patient, is not restricted to terminally ill patients, and does not exclude incompetent patients with advance directives.³

Physicians are obligated to report each case of assisted death to a Regional Review Committee (hereafter RTE, the acronym for the Dutch *Regionale Toetsingscommissies Euthanasie*, translated “Regional Review Committee”) consisting of a physician, a legal expert, and an ethicist. Formerly a Public Prosecutor inspected each case. Now such oversight is offered only to those cases that have been judged by the RTEs as not meeting the legal conditions. The RTEs have a leading role in the regulation, because their judgments are confidentially decided, final, and cannot be appealed.⁴ Since 2012, an experienced secretary to each RTE classifies the reported cases because of the sheer volume of cases. Those cases classified as “raising questions” are judged at the RTEs’ plenary convocations. Other cases classified as “not raising questions” are judged by their members individually. If a member still questions such a case,

Jacob J. E. Koopman, “Developments in the Practice of Physician-Assisted Death Since Its Legalization in the Netherlands,” *Dignitas* 23, no. 2 (Summer 2016): 11-14.

it is referred to the plenary convocation judgment. The RTEs have set out their procedures in a Code of Practice, which is available in English.⁵

The procedure of the RTEs was challenged only once in 2014. A physician, having fruitlessly advised as a consultant against the assisted death of a patient with a psychiatric disorder, was subsequently interrogated by an RTE; after which, he reported feeling humiliated and denigrated by its members. This critique has led to the installation of an independent committee to handle complaints—except that it is not possible to request review of an RTE’s decision.⁶

The Numbers and Characteristics

The number of reported cases of physician-assisted death has risen steadily from 1,882 in 2002 to 5,516 in 2015, corresponding to 1.3% and 3.7% of all deaths in the Netherlands, respectively (Figure 1). Over the last year, this number has continued to rise with 210 cases, but due to an increase in the total number of deaths, the percentage of cases of physician-assisted death decreased slightly

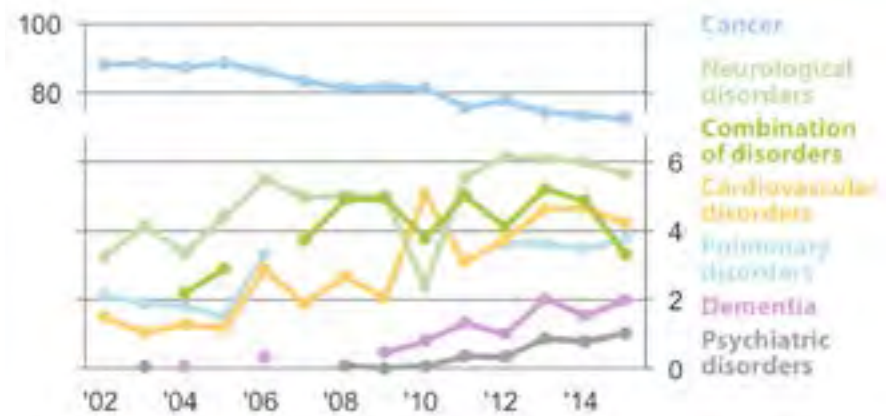


Figure 2. The percentages of cases of physician-assisted death because of cancer (—, on the left scale) and those because of other disorders (—, —, —, —, —, —, on the right scale) relative to all cases of physician-assisted death in each year.

from 3.8% to 3.7% relative to all deaths. Around 80% of the cases are classified by the RTEs as “not raising questions.”⁷

Of the 43,196 cases reported from 2002 through 2015, the RTEs have disapproved 79 (0.2%, Figure 1), with a maximum of 10 per year, mostly because of inadequate consultation of an independent physician or a medically faulty execution. In none of these cases has a physician been prosecuted.⁸

become more common, accounting for 109 (2.0%) and 56 (1.0%) cases, respectively, in 2015. Cases executed because of a combination of mostly age-related disorders have hovered around 4.5% in recent years (Figure 2). The numbers of cases executed by a general practitioner and at the patient’s home have remained stable, and while fewer cases are executed by a hospital specialist (from 11.0% to 3.3%) in a hospital (from 11.1% to 3.5%), more cases are performed by other physicians (from 2.2% to 11.0%) in healthcare facilities like nursing homes and hospices (from 4.9% to 14.8%).⁹

The numbers and characteristics of reported cases of physician-assisted death vary between regions. The numbers relative to all deaths have increased from 1.0% to 3.5% in the southern provinces, from 1.3% to 3.0% in the northern provinces, and from 2.4% to 5.9% in North Holland, which includes the national capital Amsterdam. In North Holland, assisted death is less often executed in the form of euthanasia, by a general practitioner, at home, and/or because of cancer as compared with the other regions. This variation cannot be explained by demographic, socioeconomic, or health-related differences between the regions.¹⁰

Since the aforementioned data comprise only reported cases of physician-assisted death, it is essential to know whether physicians report all cases. When interviewing physicians, 98% declare to report all cases. However, when evaluating cases of

While physicians have long been reluctant to assist in the death of patients with dementia or psychiatric disorders... such cases have become more common...

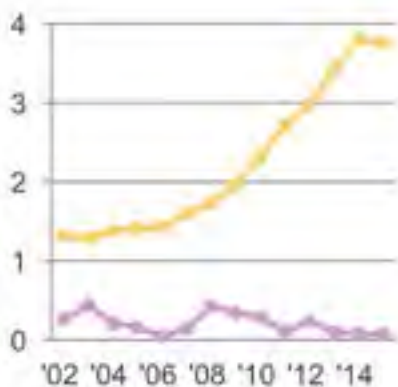


Figure 1. The percentage of cases of physician-assisted death reported to the RRCs relative to all deaths in each year (—) and the percentage of cases disapproved by the RRCs relative to all reported cases in each year (—).

Most cases of physician-assisted death were executed in the form of euthanasia instead of assisted suicide (≥89% of all reported cases in each year), because of cancer (≥88%), by a general practitioner (≥86%), and at the patient’s home (≥79%). However, these characteristics have shifted. The number of cases of euthanasia, as opposed to assisted suicide, has increased from 89% to 96% of all cases. The number of cases executed because of cancer has decreased from 88% to 73% (Figure 2). While physicians have long been reluctant to assist in the death of patients with dementia or psychiatric disorders—reflected by only incidentally reported cases in the early years, such cases have

death, physicians appear to have reported 80% of cases in 2005 and 77% in 2010. Of the non-reported cases, 79% in 2005 and 98% in 2010 is regarded by the physicians to concern “control of symptoms” or “palliative sedation” rather than “termination of life.” In these non-reported cases, morphine and benzodiazepines are used rather than muscle relaxants and barbiturates—as is prescribed for assisted death—and life is shortened by less than a week in 90% of the cases.¹¹ The non-reporting undermines the controllability and reviewability that are pursued by the reporting procedure which form the foundation of the Dutch legislation of physician-assisted death.¹²

The Justification

In the initial debates and legal cases, assistance in death was justified as an act of mercy by a physician who found himself in a situation beyond medical control or a state of emergency, in which he experienced a conflict between his duties of preserving life and alleviating suffering.¹³ Such a situation had become more common with the expansion of medical technologies to sustain life. Public awareness of such situations was raised by a physician, who pled in a controversial publication from 1969,

Human life may be ended by a physician. . . . He kills the patient. It reads so cruelly: that the physician kills the patient. It seems inappropriate. However, it is inappropriate to make the fully incompetent, long defeated, dying and already dead to vegetate further. That should be unusual. That is in any case cruel.¹⁴

Appeals to the patient’s autonomy as a justification of assisted death were less dominant. A year before its legislation, the Minister of Justice and Minister of Health declared,

This possibility for a physician can, however, never be explained as a patient’s right to an end of life. . . . We emphatically do not go so far as to mean that anyone who has no will to live anymore, also must have the possibility to end his life or to have his life ended.¹⁵

Such appeals nonetheless have a long history. Already in 1973, a group of around

1300 people founded the Dutch Society for Voluntary Euthanasia, later renamed into the Dutch Society for a Voluntary End of Life (NVVE).¹⁶ This sentiment was stimulated in 1991 by the widely discussed plea of a former justice of the Supreme Court, writing,

My ideal is that old people who are left to themselves can go to a physician . . . to obtain the means with which they can, at the moment that it appears designated to them, terminate their lives in a manner that is acceptable for themselves and for their neighbors.¹⁷

The NVVE has become a large and influential organization with an increasing number of members (Figure 3).¹⁸ Its goals encompass,

Advancement of use and social acceptance of existing legal possibilities towards free choice for the ending of life. Advancement of social acceptance and legal regulation of free choice for the ending of life in situations which are not within the scope of existing legal possibilities. Recognition of free choice for the ending of life (and assistance thereby) as a human right.¹⁹

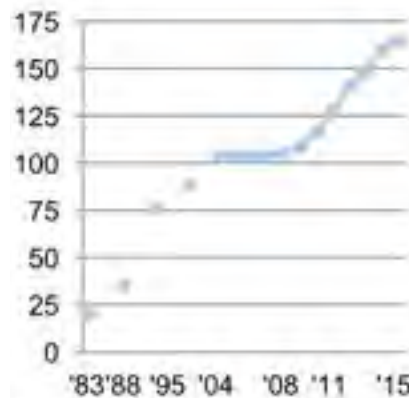


Figure 3. The number of members of the NVVE throughout the years in thousands.

To reach its goals, the NVVE advises its members about, campaigns and lobbies for, teaches at high schools on, and organizes conferences and other events with regards to assistance in death.²⁰

The NVVE and at least five other organizations have striven after the recognition of the autonomy of the elderly to freely

choose for assistance in death. A petition in 2010—named *Uit Vrije Wil* (hereafter referred to by my translation By Free Will) and supported by almost 117,000 civilians—compelled Parliament to take into consideration that,

At any moment, we can come to the conclusion that the value and the meaning of our lives have decreased to such an extent that we prefer death over life. . . . Then we wish to die, worthily and peacefully, preferably in the presence of dear family and friends. . . . By Free Will is of the opinion that assisted death of elderly who request for it, should no longer be punishable.²¹

The government has, in response, asked a committee of experts for advice. Although this committee concluded that, “it is not desirable to widen the present legal possibilities concerning assisted death,”²² a parliamentary party is currently preparing to introduce a bill that would extend these legal possibilities to elderly who are “ready to give up on life.”

A striking paradox in the appeals to patient autonomy is the emphasis on the physician’s assistance, reflected in numbers as the great and increasing preference of euthanasia over assisted suicide. If assistance of a physician is unavailable, it may be expected from family and friends, as revealed by a law case in 2015. A son of a 99-year-old woman, who was ready to give up on life and suffered from multiple mostly age-related disorders, was convicted for assisting in her suicide. He was not punished, though, because he had faced a conflict of duties and had met the legal conditions, precisely as prescribed for physicians.²³

The Role of Physicians

Physicians represented by the KNMG have had a leading role in legalization and regulation of physician-assisted death.²⁴ The “medical-professional norms” encapsulated in their guidelines, in tandem with prior court cases, specify the interpretations of the legal conditions, as has been acknowledged by the government.²⁵ These interpretations can, consequently, be changed. For example, when delineating the condition that a patient should

suffer unbearably, the KNMG guideline from 2003 holds that, “In the assessment of the suffering of a patient, some extent of subjectivity is inevitable, but there surely are professional and objectifiable elements to be recognized. . . . At least it

accordance with the medical-professional norm and acts not in accordance with the medical-professional norm can fall within the legal scope and be approved [by the RTEs].”³⁰

are insufficiently informed about the limits to assistance in death, 24% find it difficult to reject a request, 70% encounter occasional pressure to grant a request, and 64% have experienced an increase in this pressure over the last years.³²

“A striking paradox in the appeals to patient autonomy is the emphasis on the physician’s assistance, reflected in numbers as the great and increasing preference of euthanasia over assisted suicide.”

should be ‘inter-subjectively’ unbearable, which means that different physicians can empathize with it.”²⁶ By contrast, the renewed guideline from 2011 states that, “It is the patient who determines whether his suffering is unbearable. . . . The current legal scope and the interpretation of the concept of suffering are wider than many physicians hitherto assume and apply.”²⁷

Likewise, the KNMG’s guidelines have changed the delineation of disorders that qualify for assistance in death. The guideline from 2003 explains “that in cases in which the suffering does not predominantly result from a somatic disease or disorder . . . exceptional caution is required . . . and in cases in which the suffering cannot predominantly be attributed to a classifiable disorder . . . physician-assisted death is not legitimized.”²⁸ By contrast, the guideline from 2011 explains that, “It is completely defensible that vulnerability including aspects like loss of function, loneliness, and loss of autonomy are taken into account by physicians in the assessment of a request of assisted dying.”²⁹

Recently, the role of the medical-professional norms has started to erode. The Minister of Justice and the Minister of Health—following the RTEs—have contradicted the standpoint of the KNMG that an incompetent patient may only be assisted in his death if he continues to express the request captured in his advance directive. They declared in 2014, “Jurisprudence indicates that both acts in

Changes in the guidelines go hand in hand with changes in physicians’ opinions. Although a constant proportion of physicians—around 85%—are willing to assist in death, they granted 37% of all requests in 2005 as opposed to 45% in 2010. The proposition that “everyone has the right to self-determine his life and death” was supported by 47% of physicians in 2005 and by 56% in 2011 (Figure 4).³¹

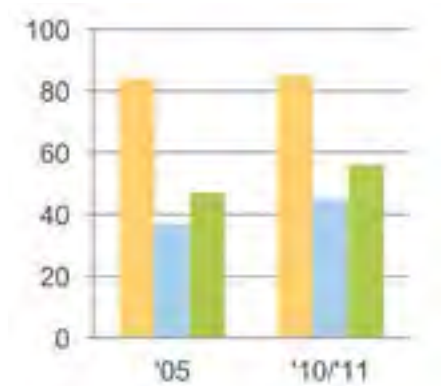


Figure 4. The percentage of physicians willing to assist in death (◀), the percentage of requests for assistance in death granted by physicians (◻), and the percentage of physicians supporting the proposition that “everyone has the right to self-determine his life and death” (◻).

In 2014 the KNMG polled physicians for their experience regarding the current possibility to assist in death. Of the 455 responders, 75% believe that the assessment and execution of requests are part of their profession, 88% feel that society should be more aware of the burden this places upon them, 60% hold that patients

Children

The Dutch legislation of physician-assisted death applies to patients 12 years and older. Since the 1990s, assisted death of newborns with severe disorders has been tolerated, discussed, and, in two legal cases, approved. To formalize and delimit its practice, pediatricians in the city of Groningen devised the Groningen Protocol in 2002, in cooperation with the Public Prosecutor. The Protocol has been adopted by the Dutch Society for Pediatrics in a national guideline, endorsed by the KNMG, and later referenced in a Ministerial Decree, but has never been implemented in law. The Protocol requires a physician to conform to the same conditions as when assisting in the death of an adult and, additionally, to exclude any doubt about the diagnosis and prognosis and to assure the consent of both parents.³³ The government established a Review Committee in 2007 to judge whether cases meet the conditions. The Public Prosecutor decides, in consideration of the Committee’s judgment, whether the physician should be legally prosecuted. However, the Committee has received only one case report to date, which was approved and suspended from prosecution.³⁴

Meanwhile, it is estimated that approximately 1% of all neonatal deaths per year are assisted in death. Of pediatricians who were interviewed, 64% deem it necessary to have this possibility, despite quality palliative care. The number of assisted deaths of newborns has decreased, however, probably because of expanded prenatal diagnostic possibilities and fear of legal uncertainties about risk of prosecution and compliance with medical practice.³⁵

Earlier this year, at the request of the Dutch Society for Pediatrics, the Minister of Health commissioned a study on

deficiencies in medical practice at the end of children's lives and established a multi-disciplinary center of expertise to advise physicians about end-of-life care for children. At the same time, contradicting the Society,³⁶ the Minister dispelled

a misconception that currently no legal possibilities exist for a physician to proceed, as an ultimate act of his duty to care, to actively terminate the life of children between the ages of one and twelve years. A physician can in such a case appeal to a situation beyond control in the sense of a state of emergency.³⁷

The End-of-Life Clinic

The NVVE founded the End-of-Life Clinic in 2012 to help patients with a request for assisted death who are “left in a lurch” by their own physicians. It employs teams of physicians and nurses that travel throughout the country to assess their requests and to provide such assistance.³⁸ With the founding of the Clinic, assistance in death has been divorced from its role in the long-lasting relationship between a physician and his patient.³⁹

In one unique case, the End-of-Life Clinic assisted in the death of a patient at her request, but against the wish of the staff in her nursing home, who asserted that she was incompetent. The Clinic euthanized her only after a court order forced the nursing home staff to comply.⁴⁰

“With the founding of the Clinic, assistance in death has been divorced from its role in the long-lasting relationship between a physician and his patient.”

The number of requests submitted to the End-of-Life Clinic have increased from 714 in its first year to 1234 in 2015 (Figure 5). Over the span of these years an average of 59% of the requests are made because of physical disorders, 36% because of psychiatric disorders, 9% because of a combination of mostly age-related disorders, and 7% because of dementia. Some requests “require urgent commitment,” as was ascribed to 277 requests in 2015, of which 72% were because of terminal

cancer and 17% because of progressing dementia. On average, over these years 24% of the requests are rejected, 21% are granted, 14% are annulled because of the requestor's death, and the remainder are under investigation or still granted by the own physician. The number of rejected requests has decreased from 28% to 23%. The most important reason for rejecting requests of psychiatric patients is an impulsive wish to die; and for those who are “ready to give up on life,” the most important reason for rejecting such request is the lack of a medical disorder.⁴¹

Why does a patient's own physician not grant the requests of their patients? The End-of-Life Clinic offers the following statistics: 43% of physicians doubt whether the request meets the legal conditions, 33% have conscientious objections as grounds for refusal, 14% lack experience with assisted death, 8% refuse because of their relationship with the patient, and 2% have other reasons.⁴²

Since its founding in 2012, the number of requests granted by the End-of-Life Clinic has increased from 15% to 30% in 2015. Consequently, the number of executed cases of physician-assisted death has risen from 51 to 365 (Figure 5), and the number of teams has been expanded from 6 to 43. Of these cases, 64% were granted because of physical disorders, 16% because of a combination of most-

ly age-related disorders, 13% because of dementia, and 7% because of psychiatric disorders. The RTEs have disapproved 4 of the 762 hitherto executed cases (0.5%).⁴³

“The ultimate goal,” of the End-of-Life Clinic, “is that in all cases the [patient's] own physician will assist in death and the End-of-Life Clinic will become redundant.” The Clinic strives to be a center of expertise in assisted death, for

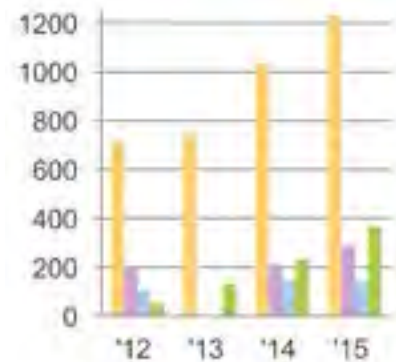


Figure 5. The numbers of received requests (x), annulled requests due to the requestor's death (y), rejected requests (z), and executed requests (w) of physician-assisted death at the End-of-Life Clinic in each year.

which it conducts research, informs the public, develops teaching material for the training of physicians, and provides guest lectures. It additionally established a consultative service in 2014, run by specialized nurses, which supports physicians who lack experience, have questions, encounter complications, or are emotionally burdened in the practice of assisted death. The support ranges from telephone advice to ongoing consultations.⁴⁴

Conclusion

The Netherlands has a long history of debating, tolerating, and regulating physician-assisted death that has been guided by the practice of physicians and the authoritative jurisprudence of the RTEs. Since its legalization, physician-assisted death has become more common without much public, legal, or juridical disapproval; it is increasingly applied because of less physical and less terminal disorders; it has become a choice for incompetent patients; it is no longer justified as a physician's act of mercy, but rather with an appeal to the patient's autonomy; it has become a possibility for unbearable suffering as experienced subjectively instead of assessed objectively; and it is not only performed in long-standing relationships between physicians and patients, but also by the quick-acting End-of-Life Clinic. Despite their disapproval, Mr. Santorum may be closer to the truth than the Dutch would like to admit.⁴⁵

- 1 Glenn Kessler has provided this quotation in “Euthanasia in the Netherlands: Rick Santorum’s Bogus Statistics,” *The Washington Post Fact Checker*, February 22, 2012, https://www.washingtonpost.com/blogs/fact-checker/post/euthanasia-in-the-netherlands-rick-santorums-bogus-statistics/2012/02/21/gIQAJaRbSR_blog.html (accessed July 12, 2016). For a video of the statement, see Michael Morse and Eugene Kiely, “Santorom’s Bogus Euthanasia Claims,” *FactCheck.org*, February 22, 2012, <http://www.factcheck.org/2012/02/santoroms-bogus-euthanasia-claims> (accessed July 12, 2016).
- 2 See both Kessler, “Euthanasia in the Netherlands,” and Morse and Kiely, “Santorom’s Bogus Euthanasia Claims.”
- 3 Heleen Weyers, *Euthanasie: het proces van rechtsverandering* (Amsterdam: Amsterdam University Press, 2004), 390–391. See also Jacob J.E. Koopman and Theo A. Boer, “Turning Points in the Conception and Regulation of Physician-Assisted Dying in the Netherlands,” *The American Journal of Medicine* 129, no. 8 (2016): 773.
- 4 See Weyers, *Euthanasie*, 392, as well as Koopman and Boer.
- 5 Regional Euthanasia Review Committees, *Code of Practice* (The Hague: 2015), <http://www.euthanasiacommissie.nl/uitspraken/brochures/brochures/code-of-practice/1/code-of-practice> (accessed July 12, 2016).
- 6 Alwin Kuiken, “Ruzie om euthanasie, verricht bij jonge geesteszieke vrouw,” *Trouw* January 11, 2014; *Klachtenregeling* (The Hague: Regional Euthanasia Review Committees, without date).
- 7 The RTEs provide data on the reported cases in their annual reports published online in Dutch, <http://www.euthanasiacommissie.nl/uitspraken>. Annual data on all deaths are freely available from the Central Bureau of Statistics, <http://statline.cbs.nl/statweb>.
- 8 *Ibid.*
- 9 *Ibid.*
- 10 *Ibid.* A more detailed description is expected to be published soon in a scientific journal in English as Jacob J.E. Koopman and Hein Putter, “Regional Variation in the Practice of Euthanasia and Physician-Assisted Suicide in the Netherlands.”
- 11 Agnes van der Heide et al., *Euthanasie en andere medische beslissingen rond het levenseinde: Sterfgevallenonderzoek 2010* (The Hague: ZonMw, 2012), 41–45; Agnes van der Heide et al., *Tweede evaluatie Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding* (The Hague: ZonMw, 2012), 98–101.
- 12 Weyers, *Euthanasie*, e.g. 321–325.
- 13 Weyers, *Euthanasie*, e.g. 77–78, 121, 408, 416.
- 14 Jan Hendrik van den Berg, *Medische macht en medische ethiek* (Nijkerk: Callenbach, 1969), 48, (author’s translation, hereafter indicated by AT).
- 15 *Kamerstukken II* 1999/00, 26691, no. 6, 30, (AT). See also Weyers, *Euthanasie*, 399.
- 16 Weyers, *Euthanasie*, 101.
- 17 Huib Drion, “Het zelfgewilde einde van oudere mensen,” *NRC Handelsblad* October 19, 1991, (AT).
- 18 See Weyers, *Euthanasie*, 101, 177, 304. See also the information about the NVVE which is provided in its statute and annual reports published online in Dutch, <https://www.nvve.nl/over-nvve/organisatie>.
- 19 See NVVE’s annual reports, (AT).
- 20 See NVVE’s annual reports.
- 21 Information about By Free Will has been published online in Dutch, <http://uitvrijewil.nl> (accessed July 12, 2016), (AT).
- 22 Paul Schnabel et al., *Voltooid leven: over hulp bij zelfdoding aan mensen die hun leven voltooid achten* (The Hague: Adviescommissie Voltooid Leven, 2016), 16, (AT).
- 23 ECLI:NL:GHARL:2015:3444.
- 24 Weyers, *Euthanasie*, 412–414.
- 25 *Handelingen II* no. 27 (2000/01) 2250.
- 26 *Standpunt Federatiebestuur KNMG inzake euthanasie 2003*, VI.07, version 3.0 (Utrecht: Koninklijke Nederlandse Maatschappij tot bevordering der Geneeskunst, 2003), 13. This can be accessed at <http://www.knmg.nl/web/file?uuid=8c5806df-66ba-4c8a-9e68-95052c69a20f&owner=a8a9ce0e-f42b-47a5-960e-be08025b7b04&contentid=41999> (accessed July 12, 2016), (AT).
- 27 *De rol van de arts bij het zelfgekozen levenseinde* (Utrecht: Koninklijke Nederlandse Maatschappij tot bevordering der Geneeskunst, 2011), 20–21, 24, (AT).
- 28 *Standpunt Federatiebestuur KNMG inzake euthanasie 2003*, 14, (AT).
- 29 *De rol van de arts bij het zelfgekozen levenseinde*, 22, (AT).
- 30 *Kamerstukken II* 2013/14, 32647, no. 30, 5, (AT).
- 31 van der Heide et al., *Euthanasie*, 11–12; van der Heide et al., *Tweede evaluatie*, 85–87, (AT).
- 32 Eric van Wijlick and Gert van Dijk, “Dokters hikken soms tegen euthanasie aan,” *Medisch Contact* no. 1/2 (2015): 16–19.
- 33 *Zorgvuldigheidseisen rond actieve levensbeëindiging bij pasgeborenen met een ernstige aandoening* (Utrecht: Nederlandse Vereniging voor Kindergeneeskunde, 2005, geactualiseerde versie 2014), 6–10; *Medische beslissingen rond het levenseinde bij pasgeborenen met zeer ernstige afwijkingen* (Utrecht: Koninklijke Nederlandse Maatschappij tot bevordering der Geneeskunst, 2013), 67–69; “Regeling beoordelingscommissie late zwangerschapsafbreking en levensbeëindiging bij pasgeborenen,” *Staatscourant* no. 3145 (2016).
- 34 The Review Committee provides data on the reported cases in their (bi)annual reports published online in Dutch, <http://www.lzalp.nl/procedure/jaarverslagen>.
- 35 See *Zorgvuldigheidseisen rond actieve levensbeëindiging bij pasgeborenen met een ernstige aandoening*, 5, and *Medische beslissingen rond het levenseinde bij pasgeborenen met zeer ernstige afwijkingen*, 28–35. See also Suzanne van de Vathorst et al., *Evaluatie Regeling centrale deskundigencommissie late zwangerschapsafbreking in een categorie-2 geval en levensbeëindiging bij pasgeborenen* (The Hague: ZonMw, 2013), 77–78, 86–88, 95–97.
- 36 *Zorgvuldigheidseisen rond actieve levensbeëindiging bij pasgeborenen met een ernstige aandoening*, 5.
- 37 *Kamerstukken II* 2015/16, 32647, no. 52, 2, (AT).
- 38 The End-of-Life Clinic provides data on the requested and executed cases in their annual reports published online in Dutch, <http://www.levenseindekliniek.nl/informatie>. The citation is from its annual reports *Jaarverslag 2013*, 7; *Jaarverslag 2014*, 7; *Jaarverslag 2015*, 7, (AT).
- 39 Koopman and Boer, “Turning Points,” 774.
- 40 ECLI:NL:RBZWB:2015:2681. See also the Clinic’s annual report *Jaarverslag 2015*, 30.
- 41 See the annual data of the End-of-Life Clinic, <http://www.levenseindekliniek.nl/informatie>. The data on urgent cases are from the Clinic’s annual report *Jaarverslag 2015*, 22; the data on the most important reasons for rejecting cases are from *Jaarverslag 2013*, 21.
- 42 See the Clinic’s annual report *Jaarverslag 2015*, 23.
- 43 See the Clinic’s annual reports.
- 44 The Clinic’s mission is described in its annual reports *Jaarverslag 2014*, 7 and *Jaarverslag 2015*, 7, (AT). Its activities are described in *Jaarverslag 2013*, 22–23, 48–50, *Jaarverslag 2014*, 26–31, 54–58, *Jaarverslag 2015*, 26–33, 44–45.
- 45 See a similar conclusion by John Keown, “Santorom and Dutch Euthanasia: Fact-Checking the ‘Fact-Checkers,’” *National Review: The Corner*, March 19, 2012, <https://www.nationalreview.com/corner/293857/santorom-and-dutch-euthanasia-fact-checking-fact-checkers-john-keown>.

INTRODUCING OUR 2016 GBEI SCHOLARS

JACOB J. E. KOOPMAN, MD, PHD & HÉLIO ANGOTTI NETO, MD, PHD

GLOBAL BIOETHICS

EDUCATION INITIATIVE



JACOB J.E. KOOPMAN,
MD, PHD

THE NETHERLANDS
2016 RECIPIENT

Dr. Koopman comes to CBHD from the Netherlands. He graduated with honors in both Medicine and Biomedical Sciences at Leiden University Medical Center, Leiden, where he also completed doctoral

research on aging. Upon returning to the Netherlands, he will start his clinical specialist training in Internal Medicine.

Dr. Koopman's interest in bioethics focuses on end-of-life concerns. Parallel to his studies and research, he has published articles in Dutch scientific, ethical, and political websites and journals. These articles cover such issues as the meaning of human dignity, the relation between dignity and autonomy, and physician-assisted death. For the Prof. Dr. G.A. Lindeboom Institute, he has participated in a study that explores nonmedical—or perhaps supermedical—means to relieve suffering at the end of life, which will soon be developed into a book.

During CBHD's Summer Conference, Dr. Koopman presented on the developments in physician-assisted dying in the Netherlands—a version of which is published in this issue of *Dignitas*. These developments reveal a normalization and expansion of the practice of physician-assisted dying in the Netherlands and may, therefore, be of warning to countries and states that have more recently decided or are currently considering to legalize the practice. Dr. Koopman has also written a short description of these developments, together with Dr. Theo Boer, a member of CBHD's Academy of Fellows, in *The*



HÉLIO ANGOTTI NETO,
MD, PHD

BRAZIL
2016 RECIPIENT

Dr. Angotti Neto comes to CBHD from Brazil. He graduated in Medicine at the Federal University of Espírito Santo, in Brazil and has completed his residence program in Ophthalmology at the

University of São Paulo, where he also concluded his doctoral research in Medical Sciences.

Dr. Angotti Neto's interest in bioethics focuses on the legacy and culture of medical ethics, with particular interests in the Hippocratic tradition, the beginning of life, and biopolitics. He has published *A Morte Da Medicina* (Vide Editorial, 2014), a book about infanticide and human dignity, along with several articles in journals and websites.

During CBHD's Summer Conference, Dr. Angotti Neto presented a paper on the value of the Hippocratic Oath for contemporary medical culture and its classification according to the Aristotelian Theory of the Four Discourses. His research will be published as an essay in the *Legacy of Medicine* in Brazil, and is a part of a greater project in medical history and culture to reclaim a Christian Hippocratic perspective.

As a GBEI Scholar, Dr. Angotti Neto explored several questions regarding the history of medicine in Ancient Greece, in the Roman Empire, and in early Christianity. He also examined Edmund Pellegrino's life and his work utilizing CBHD's Research Library and especially The Edmund D. Pellegrino Special Collection in Medical Ethics and Philosophy.

JACOB J.E. KOOPMAN, MD, PHD (continued)

American Journal of Medicine, entitled "Turning Points in the Conception and Regulation of Physician-Assisted Dying in the Netherlands."¹

As a GBEI Scholar, Dr. Koopman has explored questions regarding end-of-life care, such as: Under what conditions can death be regarded as dignified or good? What are the responsibilities of the physician and the patient at the end of life? For this, he made use of the varied expertise of CBHD's staff and the resources in CBHD's Research Library.

Of his time with CBHD, Dr. Koopman says, "I am deeply grateful for the GBEI Fellowship. Strengthened by my experience at the Center, I hope to continue to counter the dominantly secular-liberal bioethical debates in the Netherlands."

1 Jacob J. E. Koopman and Theo A. Boer, "Turning Points in the Conception and Regulation of Physician-Assisted Dying in the Netherlands," *The American Journal of Medicine* in press, 2016. This description is freely accessible through the journal's website, [http://www.amjmed.com/article/S0002-9343\(16\)30243-1/pdf](http://www.amjmed.com/article/S0002-9343(16)30243-1/pdf) (accessed July 19, 2016).

For more information about our Global Bioethics Education Initiative, visit www.cbhd.org/gbei or contact Jennifer McVey, MDiv, CBHD Event & Education Manager at jmcvey@cbhd.org for more information. ●●●

HÉLIO ANGOTTI NETO, MD, PHD (continued)

In addition, he initiated several conversations at the Center and during the Summer Conference around his hopes to establish a network for Christian bioethics among Brazilian scholars and opportunities to collaborate with organizations in the U.S.

Dr. Angotti Neto says, "The opportunity [afforded by] the GBEI Scholars program was something that can open new avenues for research and debate in Brazil, offering a true Christian perspective for the challenging field of bioethics."

QUESTIONS?

Would you like to offer comments or responses to articles and commentaries that appear in *Dignitas*? As we strive to publish material that highlights cutting-edge bioethical reflection from a distinctly Christian perspective, we acknowledge that in many areas there are genuine disagreements about bioethical conclusions. To demonstrate that bioethics is a conversation, we invite you to send your thoughtful reflections to us at info@cbhd.org with a reference to the original piece that appeared in *Dignitas*. Our hope is to inspire charitable dialogue between our readers and those who contribute material to this publication.

BIOENGAGEMENT:

The promise and perils of advances in technology, science, and medicine have long been fertile fodder for creative works in literature and cinema. Consequently, a variety of resources exist exploring the realm of medical humanities as well as those providing in-depth analysis of a given cultural medium or particular artifact. This column seeks to offer a more expansive listing of contemporary expressions of bioethical issues in the popular media (fiction, film, and television)—with minimal commentary—to encompass a wider

spectrum of popular culture. It will be of value to educators and others for conversations in the classroom, over a cup of coffee, at a book club, or around the dinner table. Readers are cautioned that these resources represent a wide spectrum of genres and content, and may not be appropriate for all audiences. For more comprehensive databases of the various cultural media, please visit our website at cbhd.org/resources/reviews. If you have a suggestion for us to include in the future, send us a note at msleasman@cbhd.org.

BIOFICTION:



Isaac Asimov, *The Currents of Space* (Reprint edition, Tor Books, 2010). *Memory & Identity, Psychosurgery, Neuroethics.*



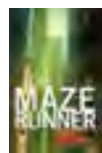
Mary Pearson, *The Jenna Fox Chronicles*

Fox Inheritance (Reprint edition, Square Fish, 2013).

Fox Forever (Reprint edition, Square Fish, 2014).



Artificial Intelligence, Biotechnology, Cognitive Uploading, Human-Animal Hybrids, Neuroethics, Personhood, Radical Life Extension, Robotics.



James Dashner, *The Maze Runner Series*

The Maze Runner (Reprint edition, Delacort Press, 2010).

The Scorch Trials (Reprint edition, Delacort Press, 2011).

The Death Cure (Delacort Press, 2013).

The Kill Order (Reprint edition, Delacort Press, 2014).



Biotechnology, Bioterrorism, Disaster Ethics, Neuroethics, Public Health, Research Ethics.

PRIMETIME BIOETHICS:



Agents of Shield (2013-present). *Genetic Engineering, Human Enhancement, Neuroethics, Research Ethics, Transhumanism.*



Between (2015-present). *Bioterrorism, Disaster Ethics, Research Ethic.*



Humans (2015-present). *Artificial Intelligence, Human-Machine Interactions, Personhood, Robot Ethics.*



Limitless (2015-present). *Cognitive Enhancement, Emerging Technology, Genetic Ethics, Human Enhancement, Neuroethics, Research Ethics, Transhumanism.*



Nikita (Season 3 & 4, 2012-2013). *Biotechnology, Bioterrorism, Nanotechnology, Neuroethics, Research Ethics.*



Person of Interest (2011-present). *Artificial Intelligence, Human-Machine Interactions, Personhood, Privacy.*

TOP BIOETHICS NEWS STORIES: MARCH – MAY 2016

BY HEATHER ZEIGER, MS, MA
RESEARCH ANALYST

“Zika Virus Kills Developing Brain Cells” by Gretchen Vogel, *Science*, March 4, 2016

As fear of the Zika virus spreads nearly as quickly as the pathogen itself, two new laboratory studies offer the first solid evidence for how it could cause brain defects in babies: The virus appears to preferentially kill developing brain cells. (<http://tinyurl.com/hpuu5x2>)

“Zika Babies Reveal Our Society’s Deep, Dangerous Prejudice against Disabilities” by Martina Shabram, *Quartz*, April 14, 2016

Much of the media coverage of the Zika virus has focused on the disabilities and deformities associated with microcephaly, and on the difficulties faced by women who are pregnant with, or have given birth to, babies with the condition. . . . But as a disability-rights scholar, what concerns me is that *[sic]* the language and imagery we use to discuss disability. Too often, the narrative surrounding microcephaly relies on familiar—and disturbing—assumptions about what kind of lives are worth living. (<http://tinyurl.com/z5smt2b>)

Perhaps the most popular bioethics headline this past spring is about the Zika virus. Zika, a mosquito-borne virus, has been present in Brazil for several years, but recently Brazilian doctors realized a correlation between contracting the Zika virus and babies born with microcephaly. Zika has raised several bioethics questions including loosening restrictions on abortion in countries that have the highest incidence of Zika infection, making contraceptives and morning-after pills available, and questioning how research on fetal tissue has helped study the virus. Shabram suggests that our response to Zika demonstrates our prejudices against disability.

“Islamic State Using Birth Control to Keep Supply of Sex Slaves: NY Times” by Idrees Ali and Diane Craft, *Reuters*, March 12, 2016

The Islamic State is using several forms of contraception to maintain its supply of sex slaves (<http://tinyurl.com/hrwylop>)

“The Underbelly of Syria’s War: A Thriving Trade in Human Organs” by Ahmad Haj Hamdo, *UPI*, May 12, 2016

The illegal trade in human organs has become widespread in Syria and neighboring countries, medical officials and victims say, with cross-border networks exploiting thousands of desperate Syrians. These networks purchase transplantable organs such as kidneys and corneas from Syrians and ship them to neighboring countries, where they disappear into the murky world of the international organ trade, they say. (<http://tinyurl.com/zfhfqqo>)

“Syrian Conflict: MSF Says Deadly Air Strike Hit Aleppo Hospital” *BBC*, April 28, 2016

At least 14 patients and three doctors have been killed in an air strike on a hospital in the Syrian city of Aleppo, the charity Medecins sans Frontieres (MSF) says. . . . Local sources blamed Syrian or Russian war planes. The Syrian military has denied targeting the hospital. (<http://tinyurl.com/ha88v63>)

Amidst the violence and humanitarian disasters resulting from the turmoil in the Syria and Iraq, has been the emergence of several issues of bioethical relevance. The Islamic State has abducted around 5,000 Yazidi men and women. Many of these women and girls have been raped and sold as sex slaves. Poverty has caused many in Syria and Iraq to sell their organs on the black market. And, against the Geneva Conventions, hospitals run by Doctors without Borders have

been the targets of attacks during the Syrian conflict.

“‘Undue Burden’ on Trial in SCOTUS Abortion Case” by Drew Gerber, *U.S. News & World Report*, March 15, 2016

In the 1973 landmark *Roe v. Wade* case, the Supreme Court gave constitutional protection to a woman’s right to an abortion. But in 1992, the court in *Planned Parenthood v. Casey* [sic] amended that right somewhat. States could restrict abortions to protect women’s health as long as those limits did not create an ‘undue burden.’ Now, 43 years after the landmark decision in *Roe*, the court must decide exactly what that phrase means. (<http://tinyurl.com/hfuvrlx>)

While conspicuously absent from the political debates, abortion has been in the news as state courts and the U.S. Supreme Court hear cases that challenge whether legislation that puts additional regulations on abortion are Constitutional. This past spring the U.S. Supreme Court heard a case on a Texas abortion law that would require doctors to have hospital admitting privileges and abortion clinics to be held to the same standards as ambulatory surgical centers. As this article was going to press, the Court decided against the Texas law in a 5-3 vote (<http://tinyurl.com/zsbvvyus>).

“Opioids Are Bad Medicine for Chronic Pain, Say New Federal Guidelines” by Harriet Ryan and Soumya Karlamangla, *The Los Angeles Times*, March 15, 2016

Federal health officials speaking in unusually blunt terms Tuesday called on the American medical community to turn away from treating common ailments with highly addictive painkillers, saying the nation’s prescription drug

epidemic was a “doctor-driven” crisis. (<http://tinyurl.com/hrdjzlx>)

“US Bill Targets Babies Born Dependent on Opioids” by John Shiffman and Duff Wilson, *Reuters*, March 23, 2016.

A bill that aims to protect babies born to mothers who used heroin or other opioids during pregnancy was introduced on Wednesday [March 23] in the House as part of the government’s response to a Reuters investigation. (<http://tinyurl.com/hlbdelz>)

Many people believe that one of the causes of the current opiate drug epidemic is overprescribing opioids for chronic pain. Studies show that many people share their prescriptions and will stoke their addiction by obtaining more pills from multiple doctors. The Centers for Disease Control and Prevention released new guidelines calling upon doctors to find other ways to help patients deal with chronic pain. Additionally, both the U.S. House and Senate drafted bills that would protect babies born addicted to opioids. Current treatments for newborns are controversial because it involves providing them with small amounts of methadone, which is not FDA approved for infants.

“In IVF, Questions about ‘Mosaic’ Embryos” by Kira Peikoff, *New York Times* April 18, 2016

Now high-resolution, next-generation sequencing has sharpened the view, and researchers are finding something surprising: About 20 percent of embryos have both normal and abnormal cells, and the percentage increases with maternal age. These so-called mosaic embryos have long been known, but they have been detectable during an active IVF cycle only in the last year. At least some of these embryos seem to mature into healthy children. (<http://tinyurl.com/zc3mfve>)

“Abnormal Cells Not a Sure Sign of Baby Defects, Finds Academic Who Had Healthy Child at 44 Despite Risk” *The Telegraph*, March 30, 2016

Embryos with abnormalities may still develop into healthy babies, suggests a new study by a Cambridge professor who gave birth to a healthy child at the age of 44 despite a test showing a high chance he might develop birth defects. Researchers found that abnormal cells in the early embryo are not necessarily a sign that a baby will be born with a birth defect such as Down’s Syndrome. (<http://tinyurl.com/j32qlzq>)

Genetic testing of embryos may not be as definitive as was once thought. Cambridge professor Magdalena Zernicka-Goetz gave birth to a healthy boy after CVS tests indicated that he would likely be born abnormal. Another study showed that many embryos are actually “mosaic” embryos, meaning they have combination of normal and abnormal cells. Some of these mosaic embryos may ‘self-correct’ and grow into healthy children, raising additional concerns that often results like these prompt parents to abort the pregnancy or discard the embryo.

“Canadian Prime Minister Seeks to Legalize Physician-Assisted Suicide” by Ian Asten, *The New York Times*, April 14, 2015.

The government of Prime Minister Justin Trudeau introduced legislation on Thursday to legalize physician-assisted suicide for Canadians with a “serious and incurable illness” The proposed law limits physician-assisted suicides to Canadians and residents who are eligible to participate in the national health care system, preventing a surge in medical tourism among the dying from other countries. (<http://tinyurl.com/z82s6gf>)

“California to Permit Medically Assisted Suicide as of June 9” by Lisa Aliferis, *NPR*, March 10, 2016.

California Gov. Jerry Brown signed landmark legislation last October that would allow terminally ill people to request life-ending medication from their physicians. . . . [T]he End of Life Option Act will go into effect June 9. (<http://tinyurl.com/gop39ck>)

Physician-assisted suicide made headlines this spring as both Canada and California posted June 6 and June 9 as the dates that their laws allowing medically-assisted suicide go into effect. These laws come at the same time that reports from The Netherlands and Belgium show an increase in the number of people dying from physician-assisted suicide (cf. <http://tinyurl.com/h24tvdj>). Their reports included increases in the number of people approved for medically-assisted suicide due to mental illness.

“Genetically Engineered Pig Hearts Survive a Record-Breaking Two Years Inside Baboons” by Rachel Felton, *The Washington Post*, April 15, 2016

In 2014, researchers led by Muhammad M. Mohiuddin . . . , announced that hearts from pigs with the human thrombomodulin gene added to their genomes had survived in baboon hosts for an average of 200 days, with some pushing past a year. . . . Now they’ve beaten that record. In a study published Tuesday [April 12] in *Nature Communications*, Mohiuddin and his colleagues report a median survival of 298 days. One graft host survived for 945 days. (<http://tinyurl.com/hkzg9tg>)

Several news items this spring speculated on using pigs to solve the shortage of organs for those patients in need of organ transplants. In this case, genetically altered pig organs were grafted into a baboon to test for immune resistance. Other research has involved making human/pig chimeras so that human organs can be grown in a pig’s body and then harvested for donation. Both involve adding human genes or human stem cells to a pig embryo. While this research may solve one ethical dilemma, it raises many others.

For the latest bioethics news updates, events, and relevant journal articles visit bioethics.com.

updates & activities

STAFF TRANSITIONS

Without the assistance of our part-time office, event, and research staff, many of the things that CBHD does would not be possible. All of us at the Center wish to extend special thanks to Andrew Kaake (Research Assistant) for his contribution to the work of the Center over the past year.

CBHD welcomed Bryan Just (Research Assistant) as a new part-time staff member over the summer. Bryan is an incoming graduate student in Trinity Evangelical Divinity School.


INTERNSHIPS

The Center was pleased to host Ben Parks, a dual-degree MA Bioethics and MDiv student, to serve as an adult education & research intern for the spring semester and early summer. Ben worked on a variety of projects involved with expanding the Center's resources, including work on content for our CBHD.org and EverydayBioethics.org sites and the Christian BioWiki. Additionally, Ben presented an overview of bioethics to a college-aged ministry at a local church. Ben was accepted to the PhD program in Theology and Health Care Ethics at Saint Louis University.


MEDIA RESOURCES

 CBHD.org on
Twitter: @bioethicscenter

 Bioethics.com on
Twitter: @bioethicsdotcom

 *The Bioethics Podcast* at
thebioethicspodcast.com

 Facebook page at
facebook.com/bioethicscenter

 LinkedIn page at linkedin.com/company/the-center-for-bioethics-and-human-dignity

 YouTube at
youtube.com/bioethicscenter

 The Christian BioWiki
christianbiowiki.org

STAFF

MICHAEL COX, MA

- Facilitated the late April Theological Bioethics Roundtable Discussion of Jean-Claude Larchet's, *Theology of Illness*.

PAIGE CUNNINGHAM, JD, PHD (CAND.)

- Was interviewed on "Brian and Kathleen Mornings" (Moody Radio, Cleveland) on several occasions to discuss the 14-day limit for experimenting on embryos, babies who are born healthy after diagnosis of Down syndrome, and gene editing.
- Joined "Let's Talk with Mark Elfstrand" on several occasions to discuss synthetic human genomes, fatherless babies, and sex-selection.
- Was featured in two informational videos in April with The Ethics and Religious Liberty Commission to discuss Christian perspectives on the use of surrogacy and the

importance of preaching on bioethics and the dignity of life.

- Contributed one column on uterus transplants for her "Biohazards" column in the Spring issue and another one on fetal tissue procurement for the Summer issue of *Salvo*.

MICHAEL SLEASMAN, PHD

- In March, presented "Engaging Technology and the Christian Life: Thoughts for Equipping Students" for the TIU ResLife Staff Training.

HEATHER ZEIGER, MA

- Contributed essays on "Sex Trafficking" and "From Me to Eternity: Does Virtual Immortality Await You in the New Lifelogs?" for the Summer issue of *Salvo*.

ON THE CBHD BOOKSHELF

For those interested in knowing what books and articles the Center staff have been reading and thought worth highlighting. **Notes that the resource includes material by members of the Center's Academy of Fellows.

Articles of Note:

Blendon, Robert, Mary Gorski, and John Benson. "The Public and the Gene-Editing Revolution." *New England Journal of Medicine* 374, no. 15 (2016): 1406–1411.

Cheung, Sau, and Ankit Patel. "Accurate Description of DNA-Based Noninvasive Prenatal Screening." *New England Journal of Medicine* 372, no. 17 (2015): 1675–1677.

Clary, Erik. "Feeding the Dead? Rethinking Robert Rakestraw on the Persistent Vegetative State." *Journal of the Evangelical Theological Society* 58, no. 4 (2015): 787–801.

Elliott, Carl. "Whatever Happened to Human Experimentation?" *Hastings Center Report* 46, no. 1 (2016): 8–11.

Falk, Marni, Alan Decherney, and Jeffrey Kahn. "Mitochondrial Replacement Techniques: Implications for the Clinical Community." *New England Journal of Medicine* 374, no. 12 (2016): 1103–1106.

Fisher, Elliott, and Peter Lee. "Toward Lower Costs and Better Care: Averting a Collision between Consumer- and Provider-Focused Reforms." *New England Journal of Medicine* 374, no. 10 (2016): 903–906.

Lo, Bernard, and Mark Barnes. "Federal Research Regulations for the 21st Century." *New England Journal of Medicine* 374, no. 13 (2016): 1205–1207.

Lockhart, Nicole, Anna Smith, Latarsha Carithers, and Carol Weil. "Genomic Research with Organs and Tissues Originating from Transplant Donors: Ethical Considerations for the GTEx Project." *IRB: Ethics & Human Research* 38, no. 2 (2016): 1–7.

Norton, Mary, Bo Jacobsson, Geeta Swamy, Louise Laurent et al. "Cell-Free DNA Analysis for Noninvasive Examination of Trisomy." *New England Journal of Medicine* 372, no. 17 (2015): 1589–1597.

**Rae, Scott. "Bioethics: The Church and the Family." *Journal of the Evangelical Theological Society* 59, no. 1 (2016): 5–16.

Rulli, Tina. "What Is the Value of Three-Parent IVF?" *Hastings Center Report* 46, no. 4 (2016): 38–47.

Saloman, Daniel. "A CRISPR Way to Block PERVs: Engineering Organs for Transplantation." *New England Journal of Medicine* 374, no. 11 (2016): 1089–1091.

Schattman, Glenn. "Cryopreservation of Oocytes." *New England Journal of Medicine* 373, no. 18 (2015): 1755–1760.

Schonfeld, Toby, Hugh Stoddard, and Cory Labrecque. "Examining Ethics: Developing a Comprehensive Exam for a Bioethics Master's Program." *Cambridge Quarterly of Healthcare Ethics* 23, no. 4 (2014): 461–471.

COMING SOON: RECLAIMING THE LEGACY OF CHRISTIAN HIPPOCRATISM