PAS Ethics SIG ethics essay contest winners

1st Place
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Care or Killing: Child Euthanasia in Belgium

On February 13, 2014, after two days of debate, the Belgian Parliament voted 86 to 44 (with 12 abstentions) to amend the existing 2002 law to abolish all age restrictions on euthanasia, effectively legalizing child/adolescent euthanasia. After the votes were tallied, a man reportedly shouted "meurtrieres!" [murderers!] from the public gallery. By March 3, King Filip-Philippe had signed the amendment into law. But for many, the question remains: is this amendment murder or mercy? Clearly it is landmark legislation: no other country has legalized child euthanasia at potentially any age. This essay seeks to explore the ethical issues at stake in the Belgian Law. First, we will describe background for the law within prior legislation in Belgium and the Netherlands. Then, we will describe a case to help illustrate the issue. Finally, we will discuss arguments for and against the new euthanasia law.

Currently, euthanasia is legal only in Netherlands, Belgium, and Luxembourg. Here euthanasia is understood as voluntary active euthanasia; namely, that a physician actively ends a patient's life at a patient's request, with their voluntary informed consent. The exact definition adopted by the Netherlands and Belgium is "euthanasia is the intentional taking of someone’s life by another, on his request."

Euthanasia was legalized in the Netherlands in 2001 and shortly thereafter in Belgium; in both countries, there already existed a precedent for the practice of euthanasia. For decades, physicians were rarely prosecuted for euthanasia; according to some studies, more than 10% of deaths in Belgium were the result of "informal" euthanasia, where physicians gave drugs deliberately to hasten their death (Cohen-Almagor, Euthanasia in the Netherlands, 2005). The 2001 laws de facto legalized both euthanasia and Physician-Assisted Suicide (PAS, in which a physician prescribes life-ending drugs that the patient then takes), although PAS was not technically discussed in the Belgian law. The laws concerning euthanasia in the two countries are similar, with safeguards requiring that the patient's suffering is "unbearable", that there is no hope for cure, and that the request be made voluntarily, repeatedly, and with consideration. In the Belgian law, additional distinctions are made concerning advance directives for patients in persistent vegetative state, and whether the patient is expected to die soon or no (if not expected to die soon, the physician must request consultation from two physicians rather than one; and there must be a one month delay between the request and its performance). Based on repeated polls, it appears that there is significant public support for legalized euthanasia in these countries. Most recently, Luxembourg legalized euthanasia in certain cases in 2009. In the United States, euthanasia remains illegal, though PAS is now legal in four states: Oregon, Washington, Montana, and Vermont. Whether states will follow the BeNeLux countries in legalizing euthanasia remains unknown.
The history of child euthanasia is particularly relevant to our discussion. Under Dutch law, euthanasia is legal for children from twelve to sixteen years of age, with parental consent. In the prior Belgian law (until this 2014 amendment was passed), the person requesting euthanasia had to be either 18 years of age or an emancipated minor. Under the new amendment, there is now no lower age limit, but the child must show "a capacity of discernment and be conscious at the moment of the request", and the case must be a "hopeless medical situation of constant and unbearable suffering that cannot be eased and which will cause death in the short term" (Watson, BMJ 2014; 348). The parents must approve, and a medical team, including psychologists and physicians must agree that the child is mature enough to understand the significance of their decision.

Before continuing, we must distinguish this law from the even more controversial practice of neonatal euthanasia, in which a physician (with parental consent) administers a lethal dose of medicine to infants deemed to have poor prognosis and unbearable suffering. Neonatal euthanasia has been practiced with some frequency and for some time in the Netherlands and Belgium. In Flanders (the largest area of Belgium) in 2000, one study found that 7% of infant deaths were caused by a "lethal (dose of) drugs administered" by a physician (Provoost, Lancet, 365:9467, 2005). In cases reviewed from the years 1997-2002 in the Netherlands, all 22 of the cases of deliberate infant euthanasia reviewed by the public prosecutor involved one of two diagnoses--hydrocephalus or spina bifida--none of them led to prosecution of the physician (Verhagen, Ned Tijdschr Geneeskd, 2005). To regulate this practice, the so-called Groningen Protocol was penned in 2004 in the University of Groningen: rules were set out that, if followed, thereby permit physicians to perform euthanasia on infants without fear of prosecution. The protocol requires that the patients have "a hopeless prognosis and experience what parents and medical experts deem to be unbearable suffering"; both parents must consent; and a second physician must agree with the prognosis and suffering. (Verhagen, NEJM, 2005). While popular support for these practices is strong in the BeNeLux countries, ethical controversy continues, particularly as the person who stands the most to lose (the infant) cannot consent. On the other hand, supporters point out a continuity of practice with the more widespread practice of elective abortion.

To illustrate the particular issues at stake in the new Belgian law allowing for voluntary child euthanasia, I will give a case. It is a hypothetical case, but one with strong similarities to cases known to the author.

Case: AJ is a ten year-old boy, who had otherwise been quite healthy. However, he presented with pain and swelling in his leg, which was eventually diagnosed as a Ewing's sarcoma. AJ underwent a long course of therapy, including chemotherapy, surgery, and, radiation. Initially, he appeared to have a good response. However, within a year (at the age of twelve) he was found to have metastatic disease, which included malignant pleural effusions. The child was in significant pain from his boney metastases; despite treatment with NSAIDs and narcotics, he would often scream, "Mom, dad, just cut my head off! I can't take it!" The parents believed him to have unbearable and meaningless suffering, and turned to the medical team. If this were Belgium, the primary physician (in this case, a pediatric oncologist) might discuss the possibility of euthanasia. The parents in turn discuss this option with the child ("Do you want the doctors just to put an end to this? To take your life sooner?"). He says yes, and repeats his answer daily.
He is evaluated by the hospital psychologist and child psychiatrist, who agree that he seems capable of understanding the consequences of this decision. The physician consults with another oncologist, who agrees with the prognosis and the extent of suffering. Therefore, with the parents and grandparents surrounding the child, the physician administers a lethal dose of thiopental, followed by vecuronium.

If we are in Belgium, this was legal. Was it ethical? Rather than dwell on the broader question of euthanasia itself, we should ask a novel question: what is it about performing euthanasia on children that makes it particularly ethical or unethical?

First, we must mention arguments in favor of pediatric euthanasia. Supporters argue that the Belgian law is a progressive step forward, a step towards greater autonomy, and respecting children's wishes. Just as adolescents' sexual choices (including their chosen sexual orientation) must be respected and protected, so too must physicians respect a child's ability to make crucial decisions about life and death--choices that concern them most of all. Supporters can also argue that, in pediatrics above all, compassion is particularly important; thus, when cure is not possible, and suffering is unbearable, society should not take from pediatricians the sole means of definitively ending this suffering. Gerlant van Berlaer of University Hospital Brussels explained, “We are just talking about the things we cannot resolve. And then, even if it is not a positive solution, we have to have some solution so these children do not suffer” (McDonald-Gibson, The Independent, 13 February 2014). To such supporters, to illegalize pediatric euthanasia is to permit needless suffering.

But many pediatricians have opposed such arguments. Shortly before the February 13 vote, nearly two hundred Belgian pediatricians penned an open letter to Parliament to delay the vote. Critics pointed out that the legalization of child euthanasia might actually create more stress for families. When a suffering child says, "I want to die!", Belgian parents must now ask whether this is to be taken literally, and endure the angst of deciding whether to euthanize their child or no. Other critics might point out that the law undermines pediatric palliative care, which continually argues that pain and depression are often under-treated. If pain is truly unbearable, why not resort to palliative sedation, which is both legal and ethically less problematic?

A third argument concerns the "slippery slope" of extending euthanasia rights further and further into areas of medicine: the concern is that laws may one day be passed that legalize even involuntary child euthanasia (taking a child's life even when the child cannot or will not consent). Certainly, the number of cases of euthanasia in Belgium has grown since the original 2001 law, and the Groningen Protocol already appears to many as a form of involuntary euthanasia. Finally, and perhaps most powerfully, critics question the entire presumption of a child's capacity to consent to euthanasia. Society has long known what science has only recently revealed: that brain development continues well into adolescence, and that children and adolescents are often less capable of making fully rational choices. If children should not be allowed to vote or watch certain movies, why should they be allowed to decide on something far more irreversible and important? And, as a corollary, critics might ask: what safeguard is there to protect children from being swayed by their parents on such complex matters: "Son, you don't want to just go on suffering, do you?"
As a pediatrics resident, I am gravely worried this new amendment to the Belgian law. I do not believe that it was necessary in the first place—pediatric palliative care should be able to address even the most intense suffering. Instead, it has opened a Pandora's box of potential harm.

2nd Place

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Fertility Preservation: Ethical considerations in using new technologies to preserve fertility for female adolescent cancer patients.

Bald, bored, and on Facebook, Kelly is 14 years old and on her second cycle of chemotherapy when we first meet. After her initial surgery for a malignant mixed germ cell tumor, she was left with one ovary and significant residual tumor burden. Early in her course, Kelly’s oncologist discussed her risk of infertility and raised the topic of fertility preservation. Kelly has strong opinions about a lot, including Justin Bieber (who she loves), chemotherapy (which she hates), sex before marriage (she plans to wait), and future motherhood (which she desires with all her heart). When presented with the options for fertility preservation, including ovarian tissue cryopreservation, Kelly was all for it, but her Mom had reservations. Her mom didn’t want anything to delay Kelly’s treatment and was entirely focused on her daughter’s chances for survival.

Kelly’s case highlights the tension that exists between the ethical principles of beneficence, or ensuring that our interventions are in the young person’s best interest and respect for persons, with a recognition of adolescents’ emerging preferences and autonomy. Both of these principles guide our approach to caring for teenagers and are reflected in our current legal framework that asks parents to make decisions in the best interest of their child before the age of majority, but allows adolescents the autonomy to consent to care related to sensitive topics. Although legally, medical decisions will fall into the category of either parental or adolescent consent, in reality, most medical decisions fall somewhere along a continuum of shared decision-making. Fertility preservation decisions are an important example of shared decision-making. Because fertility preservation involves new reproductive technologies, requires an exploration of fertility preferences, and, in this case, includes an adolescent patient, whose capacity for decision making is evolving, an ethical approach that balances best interests and autonomy supports including adolescents in the decision-making process as much as possible.

The fertility preservation options available to female adolescents are relatively new and often experimental, include significant uncertainty, and are offered in the setting of a new diagnosis of cancer which requires careful consideration of what is in the best interest of the patient. A conversation, like the one between Kelly, her Mom, and her oncologist, about fertility preservation is possible only because of recent advances in the fields of pediatric oncology and reproductive medicine. Many adolescents diagnosed with cancer benefit from advances in chemotherapy and radiation treatments and can expect to survive into adulthood, but consistently
identify infertility as a distressing potential late effect of cancer therapy (Schover 1999; Zebrack, Casillas et al. 2004; Schover 2005). Significant advances in reproductive medicine and cryopreservation techniques have allowed the extension of fertility preservation services into pediatric and adolescent populations and current practice guidelines recommend that providers discuss fertility complications and preservation regardless of the age of the patient (Loren, Mangu et al. 2013), however, they offer little guidance about how these conversations should be conducted or how fertility preservation decisions should be made for, with, or by adolescent patients. These questions are difficult to answer, in large part because utilizing newer technologies for fertility preservation in female adolescents poses a unique challenge for shared decision-making and emphasizes the ethical issues at play. The reality of fertility preservation for adolescent females is that the majority of available procedures are either experimental and require enrolling in a research protocol for access to the procedure or potentially delay the initiation of cancer treatment. As a vulnerable population, adolescent involvement in research protocols must not be undertaken lightly and their parents must provide overweight and permission if the procedure involves more than minimal risk. And while the reproductive technologies are promising, current procedures preserve a chance at future fertility, but do not ensure the possibility. Parents and adolescents must recognize that fertility preservation techniques offer very little certainty about an adolescent’s ability to achieve biologic parenthood in the future. Additionally, many adolescent cancer patients are gravely ill when they are diagnosed with cancer and chemotherapy or radiation is frequently initiated within hours or days. Adolescents and their parents may be consumed by fears about death making thoughts of life beyond this current tragedy difficult or impossible to imagine. Any delay in treatment or additional required procedure needed to preserve fertility may be seen as a threat to the adolescent’s survival. These considerations weigh heavily on parents and adolescents during their decision-making process reflecting the importance of making choices that are in the best interest of the adolescent.

In addition to considering what is in the adolescent’s best interest, respect for a young person’s emerging autonomy requires supporting teens as they develop and learn to express their preferences and values. From a development perspective, each adolescent is unique in their progression along a developmental trajectory through identity formation, sexual maturity and cognitive capabilities such that discussions about fertility preservation should be tailored to the individual adolescent adolescents. The fact that many adolescent are capable of understanding the complexities involved in medical and research settings, can consider multiple perspectives, and make decisions similar to adults by the age of 14 (Weithorn 1983; Susman, Dorn et al. 1992) should encourage greater adolescent participation in the decision making process. The developmental, informational, and relational needs of each adolescent will differ as will their abilities to identify their personal values, express their preferences, or wrestle with difficult decisions. These developmental differences within and among adolescents will require providers to demonstrate their respect for a young person’s developing autonomy by evaluating the needs of each patient individually. The importance of offering fertility preservation, lies not only in protecting future options of biologic parenthood, but also in respecting an adolescent’s emerging ability to make decisions that are in keeping with their personal preferences and values. Fertility preservation is a sexual health topic that warrants participation by the adolescent because it involves an understanding of gender identity, sexual orientation, relationships, and sexual experiences. As a sensitive topic, fertility preservation raises complex ethical issues related to
confidentiality and consent. Adolescents will differ in their comfort with talking about topics of fertility and sexuality with their parents and with their providers. Family communication about relationships, sex, and family planning differ widely and respect for the young person and their role within a family requires providers to take these differences into account. Respectful consideration of the adolescent as an individual also shows respect for that particular adolescent in their role as part of a larger family, community, and cultural unit. Studies of adolescent cancer survivors demonstrate significant variability in young peoples’ desire for parental involvement at various stages of fertility discussions (Nieman, Kinahan et al. 2007; Crawshaw, Glaser et al. 2009). Research also suggests that young people may have very strong fertility preferences and may place significant value on a future role as a biologic parent (Schover 2005), and while stereotypes portray adolescents as being inconsistent and unstable, clinical experience suggests that many have stable values and preferences, and, since no data exists on the stability of adolescent fertility preferences, respect requires providers and not to make assumptions. Out of respect for adolescents’ developing autonomy and decision-making capacity as well as their individual fertility preferences and values, they should be included in conversations and decisions about fertility preservation to the fullest extent possible.

Fertility preservation for female adolescents poses important questions about what is in a young person’s best interest and how to respect emerging autonomy while offering a unique chance to examine the roles of teens and their parents in a shared decision-making process. In the end, Kelly did not undergo ovarian cryopreservation, but was instead started on Leuprolide, a less effective fertility preservation option that did not delay her cancer treatment and might protect her remaining ovary. The decision was made jointly, between mother and daughter, and accurately captures the tension between her mother’s desire to do what is in her daughter’s best interest and Kelly’s stated fertility preferences and developing autonomy.