

PBJ

PENN BIOETHICS JOURNAL

Individual Choice and Collective Norms



Complicity in Physician Aid-In-Dying and Ethics of Modern Quarantine

PENN BIOETHICS JOURNAL

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The Penn Bioethics Journal is published twice a year by the undergraduates at the University of Pennsylvania in Philadelphia, PA.

Archived editions of the Journal and information about the submission process can be found on our website: www.bioethicsjournal.com.

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Philadelphia, PA.

ISSN: 2150-5462



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Letter from the Editor

Darby Marx
Editor-in-Chief

Dear Readers,

Thank you for picking up Volume XII issue ii of the Penn Bioethics Journal, titled “Individual Choice and Collective Norms.” Inside, you will find a Bioethics-in-Brief section, interviews with Dr. Patricia Henwood and Dr. Nina Ross O’Connor, and two articles that examine the concept of the individual within a collective context.

The first article, titled “The Public Health Ethics of Modern Quarantine: Lessons from the Ebola Crisis,” explores the ethicality of mass quarantines, called cordon sanitaire, employed during the 2014 Ebola virus outbreak in West Africa. Author Simone Wahnschafft of Georgetown University applies Dr. Nancy Kass’ moral framework to assess cordon sanitaire. In her in-depth discussion of the efficacy of cordon sanitaire, Wahnschafft explores individual rights and access to basic necessities under cordon conditions, among other considerations. She ultimately concludes that alternate public health interventions against the Ebola virus would be more effective against future Ebola outbreaks.

In the second article featured in this issue, “Complicity and the Collective in the light of Physician Aid-in-dying,” author Amitpal Singh of the University of Toronto discusses individual accountability. In particular, Singh explores whether physicians who morally object to physician aid-in-dying can be held accountable even for indirect, procedural involvement in this process. Drawing upon multiple theoretical arguments, he makes a compelling claim that they in fact are not complicit under specified conditions.

For this issue, the Penn Bioethics Journal also had the opportunity to interview Dr. Nina Ross O’Connor, who is an Associate Professor of Clinical Medicine at the University of Pennsylvania, and Dr. Patricia Henwood, an instructor at Brigham and Women’s Hospital and Harvard Medical School. Dr. O’Connor, who is also the Director of Palliative Care at the University of Pennsylvania Health System, offers a unique perspective on the challenges of practicing palliative medicine and end-of-life healthcare. In our conversation with Dr. Henwood, an emergency medicine physician, she discusses her experience in Liberia during the recent Ebola epidemic.

In addition, the Bioethics-in-Brief section, which features short pieces that discuss recent developments in the field of bioethics, can be found within the next few pages. This issue features news briefs that cover a variety of engaging topics ranging from punishment, such as the pieces about chemical castration legislation in Indonesia and lethal injection protocols in the United States, to reproductive legislation and technology, such as the briefs about a recent surrogacy lawsuit and a “three parent” baby born in New York. Other topics explored within this section include the rising cost of EpiPen autoinjectors and conversion therapy legislation.

I would like to thank the entire editorial staff of PBJ -- without your dedication, this issue would not be possible. It has been an absolute pleasure serving the PBJ community for the past year, and I look forward to watching this organization continue to grow and promote bioethics discussion. In the meantime, I encourage you to enjoy the following content, and hope that it sparks engaging discourse.

Darby Marx
Editor-in-Chief
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Examining Lethal Injection Protocols in the United States

When Ronald Bert Smith was sentenced to death in early November 2016, the state of Alabama was faced with a difficult decision concerning its lethal injection protocol. Smith's legal team objected to the use of potassium chloride in the standard three-drug cocktail administered to condemned prisoners, citing an unduly high risk of pain (McDaniel 2016). The Alabama Supreme Court reached a surprising decision: Smith was allowed to decide his own method of execution. Smith obliged, settling on a never-before-used, one-drug protocol of midazolam (McDaniel 2016).

Midazolam as a one-drug injection has never been used for an execution in the United States (McDaniel 2016). In Alabama, midazolam is used in combination with two other drugs. In response to Smith's choice, Alabama Attorney General Luther Strange stated, "while...the current lethal-injection protocol is constitutional, Defendants acknowledge that Plaintiffs' proposed...alternative is at least feasible" (McDaniel 2016). United States District Court Judge Keith Watkins directed the state to go forward with Smith's single-injection drug protocol (Faulk 2016).

In most states, including Alabama, prosecutors and juries decide if a defendant should receive the death penalty (Lewin 1995). Interestingly, Alabama is the only state in which judges routinely overrule jury decisions to not impose the death penalty (Buckwalter-Poza 2014). In Smith's case, jurors voted 7-5 in recommending life imprisonment, but Judge Lynwood Smith rejected the decision and instead opted for lethal injection (Sonawane 2016). Giving one individual the sole power to decide Smith's fate raises ethical questions concerning human rights, specifically the right to life. Both capital punishment cases like Smith's and the practice of judicial override continue to kindle a contentious ethical debate in Alabama. Lethal injections are the most common method of execution in the United States, authorized in 32 states (Vivian 2013). Until 2009, the conventional lethal injection protocol in most states consisted of administering a three-drug cocktail of sodium thiopental or pentobarbital, pancuronium bromide, and potassium chloride. However, recent drug shortages, in addition to questions about the ethicality of using controversial and untested drug combinations, have prompted some states to reevaluate their lethal injection procedures (Vivian 2013).

For example, no company in the United States has produced sodium thiopental since 2009 (Horne 2016). Faced with a looming shortage, states began illegally importing the drug from unregulated suppliers in countries like India and England, bypassing the Food and Drug Administration's registration and adequate inspection checks (Horne 2016). The Drug Enforcement Agency has since seized large quantities of illegally imported sodium thiopental (Sack 2011). Opponents of the death penalty raised concerns about the quality of the drugs, stating that expired medications could potentially lead to agonizing executions, violating the Eighth Amendment's prohibition of cruel and unusual punishments (Horne 2016). In reaction to the blatant drug trafficking, the Federal Court of Appeals ruled that the FDA

must prohibit "importation of apparently misbranded or unapproved thiopental" from unauthorized manufacturers abroad (Vivian 2013). As a result, many states changed their lethal injection protocols to use pentobarbital instead of thiopental (Horne 2016). Other states entirely scrapped their three-drug protocols, favoring instead a single injection of pentobarbital (Horne 2016).

State lethal injection protocols have significant implications with regard to the right to life, preventing human pain and suffering, and consciousness. Although the Eighth Amendment provides a foundational tenet for decision-making in capital punishment cases, multiple failed executions have involved gruesome experiences for condemned prisoners as a result of untested and unapproved drug combinations (Greenemeier 2010). Most recently, the 2014 execution of Clayton Lockett in Oklahoma sparked outrage, as witnesses reported seeing him writhing and groaning in distress, despite having been declared unconscious by officials present at the execution (Fretland 2014). The three-drug combination used in that case was an untested mixture of midazolam, vecuronium bromide, and potassium chloride (Fretland 2014).

Those who approve of lethal injection find the search for a more painless alternative, such as a single-drug injection, rather paradoxical, viewing a painful death as fair punishment for the heinous crime committed (Sarat 2014). The United States Supreme Court has upheld the constitutionality of lethal injection as a form of capital punishment. In *Baze v. Rees*, the Court favored Kentucky's three-drug method for lethal injection (Goldberg 2015).

Ronald Bert Smith's decision to use a single-drug injection as opposed to the standard three-drug cocktail is unprecedented, bound to influence not only future legislation regarding capital punishment, but also the ethical standards by which condemned prisoners on death row are judged.

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Chemical Castration Law Passed in Indonesia For Sex Offenders



Protestors march against child abuse in Indonesia.

On May 25th, 2016, Joko Widodo, the President of Indonesia, signed a decree that authorized chemical castration as punishment for convicted sex offenders who targeted children (Cochrane 2016a). This decision came after a 14-year-old girl was raped by a group of teenagers who were only sentenced to 10 years in prison, prompting public outcry. Widodo responded by announcing an increase in allowed harshness and punishment for the given offenses.

In October of 2016, the Indonesian House of Representatives voted to pass the law for chemical castration (Ravda 2016). The new law not only allows for the chemical castration of convicted sex offenders, but also presents them as candidates for execution. This controversial decision has divided the country as it argues whether or not chemical castration is ethical.

In response to the new legislation, the Indonesian Doctors Association released a statement denouncing the treatment: “Based on science and scientific proof, chemical castration doesn’t guarantee the loss or reduction of desire and potential sexually violent behavior” (Cochrane 2016b). The Association also stated that its members would refuse to administer chemical castration, as it violates its code of medical ethics (Mortimer 2016). Dr. Prijo Sidipratomo, the Ethics Council Chairman of the Association, said that he believes the appropriate punishment would be increased prison sentences to deter future offenses (Cochrane 2016b). According to Sidipratomo, chemical castration is not a long-term solution to this issue because offenders are still entitled to basic human rights, and many health complications can arise from castration, including the weakening of muscles, osteoporosis, and even death (Cochrane 2016b).

Furthermore, the Indonesian Medical Association announced that any member who performed chemical castration would be removed from the association (Parry 2016). However, being a member of the Indonesian Medical Association is a precondition for obtaining medical licensure from the government, further complicating the feasibility of the new legislation. In response, Widodo said, “[It’s fine if doctors don’t want to use it. We can use military doctors and

government doctors to do it. There are lots of people who want to do it - that’s not a problem” (Parry 2016).

Widodo has defended chemical castration and has adamantly stood by his decision. Although he is a supporter of human rights, he believes that chemical castration is an appropriate punishment: “Our constitution respects human rights, but when it comes to sexual crimes there is no compromise. In my opinion... chemical castration, if we enforce it consistently, will reduce sex crimes and wipe them out over time” (Foreign 2016). Widodo has continually taken a firm stance on sexual crimes, and believes that these offenses are “extraordinary crime[s], so the handling of [them should] also be in an extraordinary way” (Hawley 2016).

The Minister for Law and Human Rights, Yasonna Laoly, also believes that the handling of sexual crimes should be strict and firm. For crimes that result in the death or disability of the victim, the death penalty should be an option (Hawley 2016).

The Jakarta-based Human Rights Working Group (HRWG) opposes this law, claiming that the punishment is too severe. Muhammad Hafiz, acting director of HRWG, said that the law on chemical castration contradicts Indonesia’s Convention against Torture Initiative of 1984 (Sapiie 2016). Hafiz urged that the resources now being dedicated to chemical castration be redirected to providing resources for the victims of sexual abuse.

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Concerns Regarding Conversion Therapy Following Pence's Election

The recent election of Vice President Mike Pence has reawakened concerns in the LGBT community regarding the possibility of government funding for conversion therapies, also known as reparative therapies. Defined as “attempts to change someone’s sexual orientation from homosexual to heterosexual through psychological treatments or counseling,” conversion therapies have traditionally including extreme measures such as vomiting and electric shock (Chan 2016; Nutt 2016). Thankfully, these methods have largely been denounced over the past 20 years (Nutt 2016).

Pence, however, has a history of supporting these therapies. While running for Congress in 2000, Pence’s campaign platform committed to redirect funds set aside for indigent HIV/AIDS patients “towards those institutions which provide assistance to those seeking to change their sexual behavior” (Nutt 2016).

In addition, the 2016 Republican National Convention’s official platform included provisions promoting state laws to “limit which restrooms transgender people could use, nodded to ‘conversion therapy’ for gays by saying that parents should be free to make medical decisions about their children without interference...” (Peters 2016).

That governmental regulation should have a role in determining and enforcing safe medical practices is uncontroversial. However, a sovereignty’s practice of determining what is psychologically beneficial or whether it is acceptable to attempt to change one’s sexual orientation remains in doubt. In the United States, only Oregon, California, New Jersey, and Washington D.C. have instituted statewide bans on the practice of reparative therapy (Fang 2015).

However, the Therapeutic Fraud Prevention Act introduced by Rep. Ted Lieu (D-Calif), if passed into law, would make conversion therapy illegal under the Federal Trade Commission Act (Shapiro 2015).

In response to the recent election and the growing concerns of the LGBT community, New York State Legislature also introduced the “Prevention of Emotional Neglect and Childhood Endangerment Act,” P.E.N.C.E. for short, to ban the conversion therapy in the state (Chan 2016).

The ethical limits of therapeutic intervention in what many consider to be a healthy psychological state is a serious point of contention. According to the Human Rights Council, “Conversion therapy can lead to depression, anxiety, drug use, homelessness, and suicide” (HRC). Special concern has been given to vulnerable groups such as minors due to their lack of autonomy and inability to provide consent.

In February 2016, New York Governor Andrew Cuomo issued an executive order banning healthcare



Photo courtesy of Complex.com

coverage for reparative therapy in the state of New York, including a blanket ban on the controversial practice for minors.

Cuomo declared that New York “will not allow the misguided and the intolerant to punish LGBT young people for simply being who they are” (Cuomo 2016).

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The Dilemma of the “Three Parent Baby”

On April 6th, 2016, a “three parent baby” boy was born in New York City. Dr. John Zhang of New Hope Fertility Center in New York City controversially traveled to Mexico to perform a fertility procedure known as spindle nuclear transfer (SNT), leading to the conception and birth of this child.

While other “three parent” babies have been born, this marks the first time it was achieved through SNT. Like all offspring, the boy has nuclear DNA from his biological mother and father.

However, unlike most children, he received his mitochondrial DNA from a donor. Human cells have extra-nuclear DNA residing within the organelle responsible for most of our energy production – the mitochondrion.

Given its importance to biological function, mitochondrial DNA (mtDNA) mutations can manifest as life-threatening diseases (Sukernik et al. 2002). The possible lethality and high transmission of these mutations, which are maternally inherited, has led to significant interest in creating methods to bypass their inheritance.

The 36-year-old mother of the baby carries a mutation for Leigh syndrome, a severe neurological disorder that affects movement and breathing. Both of her other children passed away as a result of this mutation, one at 6 years old and the other at 8 months (Zhang et al. 2016).

Without SNT, she had little chance of giving birth to a healthy child. However, SNT is designed to ensure very low levels of the mutation in a carrier’s child by using a donor’s mitochondria. As of yet, the baby is healthy, with only about one percent of his mother’s mutant mitochondrial DNA (Zhang et al. 2016).

However, that one percent is enough to raise questions about the safety of the procedure and whether it is ethical to offer to families. With time, the percentage of mitochondria with the mutation could increase and cross a threshold to a disease state (Yamada et al. 2016).

Others have raised concerns about the possible effects on aging of inheriting mitochondrial and nuclear DNA from two different people (Latorre-Pellicer et al. 2016). If these possible limitations of SNT were to occur with a high frequency, then it would call into question the ethics of falsely advertising SNT as a viable option for mothers with mitochondrial mutations.

Some believe these safety concerns need to be further explored before performing SNT, which is a significant factor as to why it is not currently FDA approved. Additionally, some have raised concerns regarding the ethics of circumventing FDA regulations by performing the procedure in Mexico.

Notions of identity have also been called into question with regard to SNT. The Medical Research Council of the United Kingdom compares the procedure to “replacing the battery in a camera – the brand of the battery does not affect the functioning of the camera.” This suggests

a change in mtDNA does not fundamentally affect the identity of a child (Nuffield Council on Bioethics 2012).

On the other hand, bioethicist Annelien Bredenoord stated that without mitochondrial disease, “they will have a different phenotype, a different life experience, a different biography and perhaps also a different character,” (Bredenoord 2010).

Consequently, many debate whether SNT inherently influences the identity of the resulting child and what that might mean ethically.

Some scientists attribute the existing ban and pushback towards SNT in the United States to the misleading nature of the term “three parent baby.” The majority of the DNA comes from two biological parents; mtDNA is far less than 1 percent of our total DNA content. A reproductive ethicist, Dr. Gillian Lockwood, expressed her concerns regarding the term: “The biggest problem is that this has been described as three-parent [in-vitro fertilization]. In fact, it is 2.001-parent IVF” (Gallagher 2015). Dr. Richard J. Paulson, president-elect of the American Society for Reproductive Medicine, feels the term “three parent baby” is not accurate because “the genes for traits that make up a person’s appearance and other characteristics are carried in the nuclear DNA” (Kolata 2016).

A 13-year-old girl who had a donor’s mitochondrial DNA recently described her perspective on the concept of “three parents” in an interview with BBC. While she was thankful for her mitochondrial mother’s kindness, she felt she “wouldn’t want to have a relationship or connection” with her donor because “the DNA [she has] of her is just so small” (Pritchard 2014).

Ultimately, Dr. Zhang supports his decision to perform the SNT in Mexico: “to save lives is the ethical thing to do” (Johnston 2016). Despite the controversy, many are hopeful this baby boy, who was once very likely to have a fatal mitochondrial disease, will grow up to live a long, healthy life.

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Controversy Surrounding Surrogacy

Recent events in California have called into question the laws surrounding surrogacy.

In March of 2015, a deaf, single 50-year-old male postal office worker identified by the initials C.M. communicated with California mother Melissa Cook, asking her to be a surrogate for a child using her eggs and his sperm – making her both the biological egg-donor and the surrogate mother (Goldberg 2016).

However, due to unplanned circumstances, Cook found herself fostering the care of three viable embryos. C.M. voiced his concern for adequately caring for triplets, due to financial restrictions, and Melissa Cook found herself making national headlines after denying the C.M.'s request to selectively reduce one of the three embryos (Ghebremedhin 2016). Cook also mentioned that she had no intention to raise the children as her own, but was still against selective reductions for personal reasons.

After Cook consistently refused to abort one of the three embryos, C.M. allegedly threatened to “bankrupt her with medical bills.” This allegation prompted Cook to file for custody, claiming that she “went into [surrogacy] to give life, not to terminate” (Ghebremedhin 2016). Cook’s case was dismissed before civil and family court before being appealed in a federal district court.

Cook’s prosecuting attorney, Michael Caspino, argued that changes in surrogacy ordinances have stripped surrogates and their children of their rights, and advocated that these doctrines be mandated as unconstitutional (Ghebremedhin 2016). In December 2015, the court ruled in favor of Cook, and allowed her to carry out the three fetuses to term, while designating C.M. as the sole parent of the children.

When the triplets were born on February 22nd, 2016, they were rushed out of the delivery room, as C.M. had instructed that Cook would not be given the opportunity to see the children (Pierson 2016).

While reviewing the case, the court was bombarded with numerous ethical dilemmas, including the indistinct gray-area that dealt with each parents’ rights in both termination of the pregnancy, and the subsequent care of the children thereafter (Goldberg 2016). In normal cases of surrogacy, a couple provides both the sperm and egg to the surrogate, for her to serve as the “carrier” during the nine months of gestation. The case was supervised by the California Court of Appeals, which has administered numerous decision upholding women’s reproductive rights. Concerns that the case ruling would surface late into the third trimester also helped shift the decree in Cook’s favor.

Given Cook’s unwillingness to care for the children post-birth, and C.M.’s financial situation and single-parent status, there lies an ethical conflict as to the father’s ability to adequately care and provide for his three children. Cook has since filed a lawsuit to be named mother of the triplets, which would overturn California’s surrogacy law, but the case was dismissed by a federal judge in Los Angeles (Pierson 2016).

Surrogacy itself is controversial, and is prohibited in a

number of states (Goldberg 2016). This practice is legal in California, which has been the location of several controversial cases involved surrogacy (Goldberg 2016). According to Marcy Darnovsky, Executive Director of the Center for Genetics and Society in Berkeley, “[the fertility industry] is very underregulated, and we need to be taking that really seriously. California is a surrogacy-friendly state and thinks that it’s doing surrogacy the right way” (Goldberg 2016).

The case involving Cook is particularly complex, as it not only involved questions surrounding the ethicality of surrogacy, but also the laws protecting women’s reproductive rights and custody.

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Ethical Concerns Regarding Rise in EpiPen Price



Photo courtesy of NPR

For individuals with severe allergies, epinephrine autoinjectors like the EpiPen can be life-saving. In the case of anaphylaxis, a severe allergic reaction, an injection from this device can keep symptoms at bay prior to seeking medical attention. However, the EpiPen, considered to be a basic necessity medication for many, has undergone a dramatic price increase in recent years. In 2008, a pack of two of these auto-injectors cost \$100, while in 2016, the price shot up to \$600 (Mangan 2016).

The production cost of one dose of epinephrine in an EpiPen is approximately \$1 USD (Mangan 2016), which raises the question: who is benefitting from the rise in price? The EpiPen is made by pharmaceutical company Mylan, and in 2015, CEO Heather Bresch made nearly \$18 million. Her income has steadily increased since she became CEO in 2011 (Rosenthal 2016).

Many advocates have raised strong concerns regarding access to these devices given the extreme rise in price. Those who are uninsured or who have high deductibles may be forced to pay the full \$600 to receive the two-pack of EpiPens, which is currently the only way that Mylan offers the devices (Keller 2016). Research shows that a reduction in Bresch's salary by 50% can offer nearly 30,000 EpiPen packages across the country (Keller 2016).

However, she continues to take a larger salary each year, and families who are unable to afford an EpiPen at its listed price are forced to forego the life-saving device. Without any say in the matter, and with little representation in big pharma, laypeople don't stand much of a chance at bargaining for better prices. Despite the release of a generic version of the EpiPen for \$300 by Mylan in December of 2016, there is still great public outcry regarding the rise in price of these devices, given their utility and necessity.

Sanofi's Auvi-Q, the unsung competitor of the EpiPen, was released in 2013 with rave reviews regarding the new autoinjector's ability to dictate instructions on how to operate the device. The Auvi-Q seemed to bridge the gap between the lack of knowledge about allergic reactions and the public.

The competition that it gave EpiPen in the two years that it was on sale increased the gap between the EpiPen's list price and actual sale price by nearly \$100 in 2015 (Keller 2016). However, Auvi-Q was forced to leave the market, due to ris-

ing concern over its effectiveness and safety. According to Canadian outlets, 9 unconfirmed incidents occurred in which the Auvi-Q package underdosed patients and caused severe detrimental health effects.

Despite the lack of confirmation and the Auvi-Q's meeting of Food and Drug Administration standards in the United States, the product was removed from the shelves in late 2015 (PRNewswire 2015).

In January of 2017, CVS pharmacy began to sell two-packs of a generic version of the EpiPen, called Adrenaclick for \$109.99. This product is available for both uninsured individuals and commercially insured individuals, who may be able to obtain a pack for as little as \$9.99 (Swetlitz 2017).

While this marks a great stride in making these devices available, only certain populations have access to CVS stores, and EpiPen still maintains its reign over the epinephrine autoinjector market. EpiPen is simple enough for children to learn how to use it, and healthcare providers utilize it because it is easy to teach anyone in the field how to spot the signs of anaphylactic shock and administer the life saving drug.

Time will tell whether EpiPen will maintain its status as the most popular epinephrine autoinjector on the market. Whether the Auvi-Q comes back to market, which it is projected to do in 2017, Adrenaclick sales pick up steam, or the government intervenes on Mylan's price jumps, one thing is certain: the need for epinephrine will not go away.

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Interview

A Conversation with Dr. Nina Ross O'Connor

Dr. Nina Ross O'Connor, MD is currently an Associate Professor of Clinical Medicine, the Director of the Palliative Care Program at the Hospital of the University of Pennsylvania, and the Chief Medical Officer of Penn Wissahickon Hospice. She is also director of various other programs involved in hospice and palliative care at the University of Pennsylvania. In addition to Hospice and Palliative Medicine, Dr. O'Connor is also certified in Family Medicine. Currently, she is conducting research on renal palliative care.

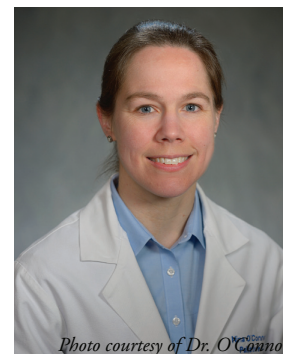


Photo courtesy of Dr. O'Connor

Penn Bioethics Journal (PBJ): Could you outline your career trajectory after graduating from medical school?

Dr. Nina Ross O'Connor (NRO): During the time I was a primary care physician, I was increasingly involved in taking care of patients in hospice. I did inpatient work and a lot of family meetings in the hospital. I was drawn to that work and so after five years of primary care, I did a palliative care fellowship at Penn. Halfway through my fellowship, I realized that I was most passionate about family care and palliative care, and I don't practice any family medicine now - I exclusively do palliative and hospice medicine. I did hospice full-time several years after my fellowship. I returned to Penn with a palliative care service at HUP, and now I'm very involved with both palliative care leadership within the health system and involved with the Chief Medical Officers of Penn Wissahickon Hospital.

PBJ: Looking into your current research, there seem to be challenges in determining the category of treatment whether staying in a hospital, hospice, or palliative care for patients. How do current physicians decide on the mode of treatment? Are there any regulations or improvements to these regulations that could be made?

NRO: Right now, the course of treatment is decided by the individual physician provider in conjunction with patients and families, and so there is a lot of variability. Some physicians are very comfortable outlining a range of options that may include very aggressive treatments - palliative treatment and even comfort-focused treatments like hospice. Some patients are able emotionally to hear that conversation and to engage with that difficult prognosis. But as you can imagine, these are really hard conversations, so some physicians have a hard time bringing them up and might not offer alternatives. They don't want to let their patients down and are really vested in trying to

provide every aggressive treatment possible. On the other side, patients and families sometimes aren't ready to have a conversation, and may like or want a list of treatments. That can be a very aggressive change in their life experience, so there are some provider considerations, and certainly family considerations and societal considerations. They may not be familiar with comfort-focused care. It is a complex issue that isn't regulated right now: it's on a case-by-case financial basis with patients and providers. Unlike some countries that have more socialized medicine and more government control of treatments and access, in our health system anybody can for the most part not have a significant survival advantage, because all these treatments are based on individual patients.

Absolutely there are some teachable tools that make these conversations little bit easier and I like to always start by asking the patient or the family member about their understanding of the illness; so I'll ask questions like, "What have your other doctors told you about what to expect?" or "What do you already know?" You want to get a sense of how much information they've gotten and whether they really digested it and processed.

“ Some physicians have a hard time bringing [comfort-focused care] up. They don't want to let their patients down and are really vested in trying to provide ever aggressive treatment possible. ”

You'd be surprised when you asked those questions how many patients and families either weren't told or didn't assimilate the information in a way that lets them move forward. So that's the first thing that I do. After that I ask open-ended questions about values and preferences, like "What's most important to you if this procedure doesn't go well? What are you hoping for? What are you worried about?"

Then once you have understanding of their illness about their values and preferences, you can make a recommendation for a treatments that makes the most sense for that patient, or something like, "Based on everything I've heard about your values, it sounds like maybe you should look for hospice." Those are some of the strategies, but it's very different from what we're taught in medical school, which entails objective questions about symptoms found, and then providing

A Conversation with Dr. Nina Ross O'Connor

information about treatment or survival. While doctors make decisions on statistics and survival curves, it's not really how patients make those decisions. Decisions are highly emotional sometimes, and they involve religious preferences or cultural issues, so we have to remember they're not making huge decisions the same way we're thinking about them numerically.

PBJ: Are there different regulations for those with cancer compared to those with renal disease in determining who receives palliative care?

NRO: Palliative care is a speciality that can be layered on top of other care. For example, at Penn we have two palliative care clinics for patients with cancer, providing more access to palliative care for cancer patients. Unfortunately, for families who aren't diagnosed with cancer, there are clinicians who either aren't familiar with how to access palliative care or the care may not be available in these outpatient settings. At Penn we don't have a clinic for patients with renal disease to have a prognosis and benefit from palliative care. In the inpatient setting, most hospitals nowadays have a palliative care consult team. It's become a standard of care to have palliative care, and so when patients are hospitalized they can usually get hospice care but of course that's very late. It would be ideal not to wait until patients are hospitalized for them to be able to get this additional support or to clarify their goals and values.

Another conflict is when patients agree with comfort care, but have a poor prognosis and would still want to go back to the hospital for something that could be treated. For example, they might still want something like palliative chemotherapy or blood transfusions, which can't be done in hospice, and so there's a subset of patients with poor prognoses but can't qualify for or don't want hospice care. We have limitations on how they can proceed, and those are the patients that palliative care really serves well.

PBJ: What would you consider as bioethical problems that you would have to tackle on a day-to-day basis?

NRO: I have a lot of conversations with patients about end-of-life treatment preferences, and also a lot of conversations with physicians about end-of-life treatment. I think some of the hardest ethical situations are when all the parties aren't talking openly: perhaps a provider hasn't been comfortable sharing a prognosis, and the patient is trying to make life decisions but doesn't have a realistic sense of their prognosis. I think those are difficult situations to navigate and something we need to really work on. That's actually the most common scenario I see. There certainly are more high-profile ethical life issues

around withholding or withdrawing nutrition and hydration, or disagreements between decision-makers about end-of-life patient care in our society. I think the most common one is just not having the conversation about prognosis, not knowing patients' wishes, and trying to navigate a complicated health system without that basic understanding of prognosis and

values. That's the bread-and-butter issue. It's not about the headline about the person that's administering to the patient - that happens once in a while, but day-in-day-out it's more of the need to have a better conversation between patients and physicians so that we can actually respect people's wishes and give them a real sense of their options.

“People get scared away from this field and may think it's really depressing but it's not; it's actually uplifting to be helpful for patients and families to ensure that families have an acceptable end of life experience.”

PBJ: What advice would you give students interested in pursuing this career in the future?

NRO: I think there's a lot of opportunity in palliative care for physicians, for nurses, and for social workers. It's really a growing field with a tremendous demand for skillful clinicians. There's a wide open field for people to grow into, and people interested in it could shadow or volunteer in a hospice or on a palliative care team. Being in the environment would be a tremendous way to find out whether this would be a fit or not. It's not for everybody. It's also tremendously satisfying in the sense of knowing that what you do every day is making a difference in a really obvious way. I would say people get scared away from this field and I think they may think it's really depressing and it's really not; it's actually uplifting to be helpful for patients and families to ensure that families have an acceptable end-of-life experience.

PBJ: What would you consider as the major challenges you have faced in palliative care?

NRO: So I think that each palliative care clinician has different cases considered challenging for them. For me, I've taken care of a few female patients with children. I think I find that situation the hardest emotionally for me, and so whenever we have small cases, we talk about it as a team. We support each other, and we don't take care of the patient alone. I think that's been really, really helpful. Another thing that's really important is that you have to recognize the patient and how your feelings about a difficult case might be influencing your care.

Interview by Catherine Huang

Interview

A Conversation with Dr. Patricia Henwood about the Ebola Virus Quarantine

Dr. Patricia Henwood is the President & Co-Founder of Point-of-care Ultrasound in Resource-limited Environments (PURE, www.pureultrasound.org), a non-profit organization focused on ultrasound education and research in the developing world with current training programs in Rwanda, Uganda and Liberia. She works clinically in the USA as an emergency medicine physician in the Division of Emergency Ultrasound at Brigham and Women's Hospital and Harvard Medical School in Boston, and also co-chairs the Global Health Subcommittee for ACEP's Emergency Ultrasound Section.



Penn Bioethics Journal (PBJ): Did you take any part in organizing quarantine protocol during your time in Liberia?

Dr. Patricia Henwood (PH): I was not directly involved in creating protocols around quarantine, and there were definitely challenges and a lot of variation in different areas in terms of how things were handled when there were suspect cases. In the context where I was working, we were working with local county investigators, and going out and doing case finding when people called with symptoms, but we didn't have any recourse to make people come into the Ebola unit at the time. There were people who were monitored by the county case investigators, but in different locations there were different policies.

I think one of the big challenges with quarantine and with monitoring in this context is that there are a lot of gray areas and a lot is open to interpretation, and I think that was the case with different areas in West Africa. That makes it very challenging for people who are either self-monitoring or under monitoring, because the actual guidelines were not entirely clear.

PBJ: Do you believe that the quarantine procedures were helpful in terms of eradicating it, or were there instances where you saw contentious human rights practices going on throughout the quarantine?

PH: With quarantine, there is tension between the individual rights and the public health and good, and I think it's a matter of what kind of level of exposure people have and what their actual risk of developing the disease is. Again, I think that there were challenges in terms of people, maybe public health officials, being concerned that people weren't being totally honest in terms of exposures. That then led to more strict monitoring and movement restriction than might have otherwise not been the case.

We also have situations like tuberculosis in the United States or such where there is a risk of the individual's freedom of movement—in these cases, the risk for the public outweighs that. It really depends on the specific context and specific cases. In some cases, things were handled well in

terms of high risk situations. I think in other cases such as broad quarantine, people become upset if they weren't necessarily exposed or have symptoms that warrant that movement restriction for them.

PBJ: Were basic necessities such as food and water ensured to quarantined populations?

PH: Again, I think that this was something that was variable in terms of different locations and different points in the epidemic. It is the responsibility of the parties coordinating that quarantine to ensure that people have adequate access to food and water and other daily living supplies they would need. I think in some cases that was done well, and I think in other cases there wasn't as much consideration because there was more concern of instituting things quickly due to concern of the spread.

Something important that might not be considered when instituting a quarantine is that when you are restricting peoples' ability to leave their home, for example, then you need to expect to provide a lot of things. Most of the time, people are not preparing to be quarantined; it's something that just happens. They need to have access to basic necessities, and preparations need to be made especially if the quarantine is not just for several days but for a longer duration of time.

PBJ: In your experience, did you observe any interactions or reactions from community leaders or from the actual community to being quarantined? Was there mutual cooperation between community leaders and healthcare officials, or did you observe any tensions between the two groups?

PH: Because most of my experience with working within Ebola treatment units, I was going to communities to work with the case investigators to bring people that were having symptoms. I wasn't spending time in communities that were actually under quarantine, but I know that there were situations where there were great relationships with community leaders and with county officials that were working on case investigations and surveillance.

A Conversation with Dr. Patricia Henwood

At an earlier point, there were periods where there were tensions with people who were exhibiting symptoms but were resistant to come for treatment, so I think things happened both ways. Again, very situation-dependent. But just as an overall caveat I can't speak to – I was not working within villages and communities that were under forced quarantine. I was working more with people on an individual basis and working with county investigators that were trying to convince people to go for treatment.

PBJ: As global citizens, how significant a role should we play during a worldwide crisis like the Ebola outbreak? How has your experience in global health shaped your views in assisting other nations in times of need?

PH: I think that it's important to realize that health systems in other countries need to have further developments not only for the good of the global community, but also for our population in the United States. It is important for the good of the populations in these contexts where infrastructure and health care is so limited, and there can be consequences for the United States if we are not playing a role in terms of helping lead these efforts to develop more robust infrastructures.

PBJ: How did you first feel knowing that someone you know might have been quarantined or might have been affected by Ebola?

PH: That is a challenging question because there are issues with quarantine, and then there are issues with getting sick. And I think there were people that were inappropriately quarantined, and it is upsetting when decisions are being made not based on the science and actual contact and/or symptoms but rather on potential misperception about acquisition of the disease. As a scientist this is definitely bothersome.

In regards to people getting sick, obviously it's concerning. Disregarding myself or my colleagues for one moment, just the sheer impact of the disease on the populations of that area and how things were spreading and the need for treatment were really concerning. That's what led me to try and get involved in the clinical work there; at the time, the need was so great. Also, colleague healthcare workers did not have appropriate personal protective equipment and thus ran the risk of getting unnecessarily exposed in that context as well. Given the enormity of the issue and the fact that there was a great need for more medical support – I went.

Interview by Carlos Dos Santos

Article

Complicity and the Collective in the light of Physician Aid-in-dying

Amitpal Singh*

Membership in collective endeavors has both positive and unsavory consequences. What implications are there for our individual accountability if the collective endeavors we participate in entail involvement in acts that we deem morally abhorrent or impermissible? This has been the concern of conscientious objectors, including recent discussions surrounding healthcare regimes providing the still-controversial service of physician aid-in-dying. I argue against the claim that even being procedurally involved in the process of aid-in-dying, say through providing a referral, a conscientious objector would be forced to be complicit. I do this by identifying a key conceptual error in the arguments of conscientious objectors who are concerned with complicity in a healthcare regime, namely that it is monistic, and thus that its single overarching purpose can be imputed to all agents who participate in it. In doing so, I lay the foundations for a broader claim that we are not complicit in the ways in which others use collective endeavors that are not straightforwardly monistic in their goals, for their personal purposes.

Introduction

Our most significant actions as moral agents, and our unintentional behavior, both rarely occur in isolation from the actions of others. We act as individuals, but also as participants in the various collective endeavors that play a central role in the pursuit of our projects. Predictably, this collective membership has both positive and unsavory consequences. Not only can we be concerned with the causal power of collective endeavors, for their heightened potential for producing harms, but there is an obvious internal concern as well: how are we ethically implicated in the various collective endeavors that have become nearly unavoidable in our lives, particularly when they lead to morally abhorrent outcomes?

More pressingly, what implications are there for our individual moral accountability if the collective endeavors we participate in entail involvement in acts that we deem morally abhorrent or impermissible?

The relationship of our individual moral accountability to the collective acts we participate in, insofar as they produce problematic outcomes, is the domain of complicity. Understanding the ways we are complicit in collective endeavors only increases in relevance as we continue to shed the illusion that our most basic actions are not morally freighted. We need look no further than the ways in which we furnish our homes, earn our livings, clothe, feed, and entertain ourselves – what most would describe as the most innocuous of everyday behavior – for the morally dubious processes that permeate them. In aggregation, these individual choices perpetuate the collective harms of exploitative labour, factory farming, or the proliferation of weapons and other destructive products. Our moral theories however, seem unequipped in condemning individuals for their role in collective endeavors. It has been the task of a growing literature to find the necessary conceptual apparatus to hold individuals accountable for their role in collective action.

To explore these questions, I first root them in the

debate surrounding physician aid-in-dying and physicians who have expressed a conscientious objection with providing this to patients (I-II). For now, we can describe physician aid-in-dying as the practice of hastening the death of a patient with that person's consent, through some causal contribution on the part of a physician. This is often (though not always) done at the request of terminally ill patients. The practice is now legal in the healthcare systems of several countries, such as Canada, parts of the United States, the Netherlands, and Belgium, with varying degrees of regulatory oversight and important differences in legal permissibility.

Following this, I explore what Christopher Kutz has called the “I-We problem” in his book, *Complicity: Ethics and Law for a Collective Age*, whereby we are unable to condemn individuals for their roles in collective harm because individually, they could be said to fail to make a difference (III). I then turn to outlining Kutz's own account, where he argues that the participatory intentions of persons can be used as the basis of finding persons complicit even when their individual contributions do not make a difference to the outcome (IV-V). I then apply this account of collective complicity to the discourse around conscientious objection, and then physician aid-in-dying in particular (VI).

Following this, I argue that Kutz's account makes the error of assuming that collective endeavors are ‘monistic,’ namely that they have a single overarching purpose that can be attributed to all participants. In the place of this, I contend that the ways others use collective endeavors of their own volition is orthogonal to our own culpability. I call this feature the ‘modularity’ of collective endeavors (VII).

Finally, I offer my own positive account for the manner in which we are complicit in collective endeavors, contending that agents are complicit when they will the same morally impermissible use of a collective as others, rather than by mere participation in it (VIII). Having done this, I argue that conscientious objectors would not be complicit for the ways in which other agents use a healthcare regime, even if that involves outcomes they deem morally abhorrent (IX).

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Complicity and the Collective in the light of Physician Aid-in Dying

I conclude with broader remarks on the need to resist the temptation to impute to us the overarching purposes to the collective endeavors we participate in; instead we should recognize that individuals remain the source of the plurality of purposes for which collectives can be useful (X).

I. A turn to the practical

Before exploring the questions above in detail, I want to root them in the context of a pressing issue in contemporary Canadian and American bioethics. My reasons for this are twofold. The first, which I have hinted at already, is that a version of this discussion is currently playing out in fierce fashion in the Canadian bioethics and health policy context, via debates on the implementation of physician aid-in-dying (PAD). In many cases, the arguments on offer would benefit from conceptual clarity that would allow for better scrutiny of their underlying assumptions. Secondly, and in the converse direction, the issues surrounding conscientious objection and the provision of physician aid-in-dying may have important implications for the way we understand complicity. In this period, the government of Canada has had the legal prerogative to construct a regime to regulate assisted dying, should it wish to do so. Though what the details of this regime should be remains a controversial subject there seems to be consensus that some sort of regime should indeed be in place, in order that proper safeguards are ensured. This is motivated by a concern for protecting the disabled and vulnerable by ensuring that only competent, consenting adults receive assistance in dying, and that PAD be integrated in the healthcare system without compromising the delivery of other services.

II. Physician-Aid-in-Dying and Conscientious Objection, controversy post-Carter

The development of the new law has also produced a whole host of controversy. Among the most prominent issues is the fact that there remain a variety of views on whether PAD is morally permissible, including among physicians. Underlying this is a tension in two competing moral principles: the right of patients to access a legally permissible service, and the negative liberty of physicians to be free from compulsion in performing acts they deem morally impermissible. Physicians who are objecting to providing PAD for these reasons are manifesting a “conscientious objection” (CO) – they have personal moral convictions, religious or secular, that lead them to reject providing PAD. We might quickly dismiss this as not really being an issue: why not simply allow physicians who are comfortable with providing a patient with aid-in-dying to do so, and require conscientious objectors to refer them to the former? In fact, there are a host of policy frameworks in Ontario, and Canada that work to this end. The College of Physicians and Surgeons of Ontario for example, recommends “effective referral” on the part of physicians who conscientiously object to any legally available medical procedure. Doctors who object to a medical procedure must refer to another willing physician (CPSO 2015). This means that they need not carry out the procedure or treatment themselves, but

nonetheless must provide referral in order that patient access is not compromised. However, this quick and easy solution seems unavailable. Some physicians object to providing referral on the grounds that it constitutes participation in what seems to them to be a morally abhorrent act. They are concerned, in other words, with complicity.

For now, I want to set aside the question of what type of healthcare regime would properly accommodate conscientious objectors. I want to first explore the relevant sense of moral complicity that conscientious objectors are concerned with. As I go on to explain, there is no obvious sense of complicity being appealed to by conscientious objectors (COs). It is not simply their own direct causal involvement that appears to motivate concerns about complicity. Rather, the source of concern is in the perception that a regime is collectively producing (what they take to be) morally impermissible harms, and moreover, that they are employed in it. This is the key concern that animates discussions of complicity, both in the theoretical and the practical.

III. Complicity in the Collective: the “I-We” problem

The moral and political traditions that have shaped our understanding of accountability largely locate responsibility for moral action within the individual. Appealing to what he calls the “distinctness of persons,” John Rawls argues that ascribing responsibility requires a concern for the actions of individuals, without which we risk compromising principles of justice (Rawls 1971). According to Christopher Kutz, our common sense morality holds much of the same individualistic sympathies.

In doing so, it fails to capture responsibility in morally abhorrent collective action. In many cases, it seems that individuals can act collectively to cause a morally problematic outcome, though it seems that individually, their actions make no difference (Nefsky 2015). In his diagnosis of this problem, Kutz argues that the Individual Difference Principle (IDP) is the notion that animates most common-sense discussions of complicity. The IDP holds that “I am only responsible for a harm if something I did made a difference to its occurrence. If substantially the harm would have occurred regardless of what I have done, I cannot be accountable for it” (Kutz 2000).

The problem then, is that this naive account of moral accountability is toothless to condemn individuals when they participate in some collective endeavors that yield moral harms. This is because by entering a collective, agents’ wrongdoing can be obscured via the claim that their individual acts made no difference to the outcome. The use of the IDP is what allows for this improper exoneration in situations where the morally problematic outcome is causally over-determined (i.e. there are two or more distinct sufficient causes).

To illustrate this, we can look to an example prominently featured in the literature: execution by firing squad, where the death of a victim by firing squad is over-determined. Counterfactually, the act of firing by any one shooter makes no difference to the outcome, because another shooter

would have killed the victim anyway¹ (Kutz 2000). Thus, on the IDP's heavily counterfactual, causal framework, each shooter could potentially absolve herself of accountability by contending that her act did not influence the outcome; "she would have died anyway," we can imagine them arguing.

This defense can be transposed to all sorts of other contexts: a meat-eater arguing that she is not responsible for the harms of factory farming because her individual actions "make no difference" to how many chickens are killed, or a polluter arguing that her individual contributions to climate change were causally inert, and thus, that she is not complicit in environmental harms (Nefsky 2011, Kagan 2011). Christopher Kutz and others suggest that accepting this justification – biting the bullet – is unacceptable.

This key failure of translating our overly individualistic account to the collective is what Kutz calls the "I-We" problem. We are unable to find agents responsible for their roles in morally reprehensible collective acts. What we need then is an account of joint action that does not obscure the complicity that individuals undoubtedly have in virtue of their roles in collective action. Kutz takes his project in his book, *Complicity: Ethics and Law for a Collective Age*, to be precisely this.

IV. Kutz on "Participatory Intention"

Broadly speaking, Kutz argues that strictly causal accounts of individual participation in collectives are misguided. Often, they fail to ascribe complicity to individuals who are indeed morally culpable. Accountability, Kutz says, is positional and relational, rather than entirely causal (Kutz 2000).

Sensitive to this, Kutz identifies the sufficient condition of moral accountability for individuals participating in collective action as that of "Participatory Intention." Participatory Intention for Kutz, is "an intention to do my part of a collective act, where my part is defined as the task I ought to perform if we are to be successful in realizing a shared goal" (Kutz 2000).

Thus, he argues, all statements about collective acts can be ascribed to the individuals participating, "because all collective action is explicable in terms of the intentionality of individuals – their motives, beliefs, and plans" (Kutz 2000). Kutz's point is that individual members have participatory intentions as part of the collective: each participant understands the shared goal, is committed to it, and recognizes the role others will play in bringing it about. It is a joint endeavor because it is recognized as such by the participants, and they act accordingly to bring its end about.

The central upshot of this claim is that there is no room for the overly causal account that the IDP relies on. On these grounds then, individuals can be held accountable for what others do as part of the collective, even if they have no direct

causal links to the problematic outcome. This amounts to what Kutz calls the Complicity Principle, which he defines as "no participation without implication" (Kutz 2000).

V. Implications for Conscientious Objectors

This example, and Kutz' broader framework in mind, we can identify a line of argument to which conscientious objectors may appeal in order to justify their claim that they cannot be required to participate in the process of PAD in any form. Any involvement in a healthcare regime that results in the killing of a patient is morally problematic for COs, because they are complicit for any harm produced by a collective, even if they make no direct causal contribution to it.

More specifically, we now seem to have the conceptual apparatus necessary to make sense of why individual physicians who are conscientiously objecting to PAD could be concerned with participation of any kind. Physicians may not be able to participate (without being complicit) in a healthcare regime in which their contributions can be teleologically traced to the assisted death of a patient, even if the causal relations are obscured.

Similarly, even if conscientiously objecting physicians that are being required to do one or two particular acts (referral, transfer or medical records etc.) appear to avoid complicity insofar as they are evaluated on the IDP, these actions are teleologically explained by their contribution to a shared end product: the assisted dying of patients. This, in turn, would render them complicit.

VI. Applying Kutz's "Participatory Intention" account to PAD

The previous section featured the beginnings of an application of Kutz's framework to the context of a conscientiously objecting physician in a healthcare regime that permits PAD. I want to explore this further, not yet with the intention of rejecting the application of it to this context, but in order to shed some light on a central issue in the account of collective complicity we have been investigating thus far. Kutz's analysis renders us culpable for actions that we have no direct causal involvement in.

With this in mind, let me attempt to go further still in applying this framework of collective complicity to a healthcare regime permissive of PAD.

This brings to light a salient feature of the discourse around CO, at least in the PAD context. The implicit suggestion seems to be that conscientious objectors can somehow be accommodated within a healthcare regime without compromising their moral convictions. In order to preserve this desire, it seems that conscientious objectors have two options.

The first is to simply bite the bullet, and dilute the claim that any degree of complicity is unacceptable. This would amount to accepting whatever degree of complicity there is in virtue of remaining in the healthcare regime, perhaps by arguing that it is sufficiently minimal. This point can be broadened: perhaps we are indeed complicit whenever we participate in collective endeavors that produce harms. This

1. Of course there are important conceptual differences between the firing squad example and the administration of physician-aid-in-dying. These include the fact that in the former case, multiple synchronous actors produce an outcome without an alternative, and in the latter, there remains the possibility of multiple diachronic actors. A patient might also come to retract a previous request for assisted-dying. The significance of these differences, and whether they are morally relevant ones, will be addressed when I examine physician-aid-in-dying directly in later sections.

Complicity and the Collective in the light of Physician Aid-in Dying

would have troubling implications, unless we are prepared to say, as was hinted at above, that some minimal degree of complicity is inevitable when participating in collective endeavors.

Without the latter addendum, a taxpayer's contributions being used by her government to purchase drones, killing citizens in collateral damage for instance, may render her complicit. Is the appropriate moral response to refuse to contribute our taxes? Perhaps we need not do this, on this first view. The other option would be to contend that somehow, the way I have applied Kutz's analysis has been too strong, and that complicity can indeed be avoided despite remaining within the collective that is the healthcare system. The latter is the strategy I take up. I do this by bringing to light a fundamental problem with the way complicity has been discussed by Kutz.

VII. A Conceptual error: the collective as monistic

i. A structural examination of Kutz's view

We have been occupied in this section with Christopher Kutz's account for complicity in collective endeavors, and the ways in which it purports to overcome the disappearance of moral accountability in cases of causally over-determined harms. Kutz's Complicity Principle purported to replace the IDP with a focus on the Participatory Intentions of those involved. A few remarks to conclude this section, particularly with regards to the structure of ascribing complicity on this view, will be useful to my eventual task of demonstrating the ways in which it is inadequate. Kutz's account begins by allowing that the individual makes no difference to the outcome, but denies that this is morally relevant.

Instead, it suggests that by participating in a collective act intentionally, where these intentions overlap with other participants, there is a (tacit or otherwise) endorsement of the collective endeavor². This participatory intention then, is the glue that binds an agent, causally efficacious or not, to the collective level goal that produces morally problematic harms. This problematic goal, or its consequences, is then imputed to each individual participating in order to find her complicit. But notice that it does not entirely do away with "difference-making." It certainly acknowledges that "the collective" is making a difference by producing harms. Participatory intentions then, serve the role of bridging the gap between the individual and the collective, in that it binds them to the causal harms of the collective project to find individuals responsible.

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2. Notice that the sense of endorsement here is very attenuated. It is not an explicit avowal of the end of a collective, but simply doing some task that is functionally related to its end.

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ii. Monism

My own strategy in this section, and those that follow, will be to offer an alternative perspective on the ways in which complicity in collective action can be more precisely understood. In order to do this, I begin by highlighting a key feature of collective endeavors. Discussions of collective complicity tend to begin from a concern with our overly individualistic conception of moral accountability, and then attempt to ground responsibility for the collective act by identifying an individual's role in producing it.

The notion that the collective has a singular purpose seems to be implicit in all of the examples. A discussion of complicity rooted on the participatory intentions of those involved seems particularly comfortable in the domain of these examples. However, I want to argue that where it breaks down is in its application to large-scale entities that are not straightforwardly monistic in their goals.

iii. The collective as the occasion for individual projects

Often, the connection between distinct individuals in a collective, such as a healthcare system, is not that they have the same ends and participate in different means for that end, but rather that the collective is simply the occasion for individuals' own, distinct, plural projects. Agents participate in a collective because it provides a more efficacious means to their personal, and often varied goals. The entity itself, however, is simply the condition of possibility for the pursuit of these varied goals. This can be brought out by identifying an error in Kutz's own account, when he argues, non-standardly, against what is commonly thought to be an "analytic principle of action theory," namely that an agent who wills the means of an action, wills the end of an action (Kutz 2000).

Kutz maintains that it is possible to will the means without simultaneously willing the end, offering the example of a dissident doctor who is called to save the life of an oppressive dictator whom he hates. The means to both ends, saving the dictator and acting in accordance with a duty to provide medical assistance, accidentally overlap. Thus, the means to the end of acting in accordance with his medical

duty is willed, but only insofar as offering medical treatment is a means to that particular end. In this sense, saving the dictator is a foreseen, but unintended consequence of the agent's true goal, which is acting in accordance with his medical duties. The agent need not will all of these ends.

This last finding is crucial for determining complicity in a collective. Agents need not, and I would argue often do not, enter collectives in order to serve some single, prior established end. Rather, they enter a collective endeavor because it facilitates their own private projects. Simply engaging in a collective, in the way that the physician above engages in a healthcare regime, does not require us to endorse all the ways in which a collective is used for the distinct projects of its participants.

This of course is what allows us to engage with those whom we disagree with in their fundamental moral commitments. We are not complicit for everything done under the auspices of a collective endeavour, because individuals in these collectives have distinct projects, where the organization is simply the locus of overlapping means to those individual ends.

iv. Two features of non-monistic collectives, avoiding the 'You-I' problem

It seems difficult to offer a straightforward account of the 'sole role' of many of the collective entities that we regularly engage with. This difficulty swells if we take into consideration the varying self-characterizations that individuals will offer of their respective roles in collectives that are non-monistic. Ascribing a 'sole role' to a healthcare regime, for example, that will be sensitive to the varied projects of the palliative care physician, janitor, nurse, ER doctor, and fracture patient, is a challenging, if not impossible task. This difficulty, I think, suggests to us that there is no such singular 'goal' of a collective in many instances. Rather, when they are not straightforwardly monistic, they are merely instruments, or "amoral marketplaces" in which agents' diverse projects are pursued.

The position I have taken has two commitments in understanding the concept of collectives. The first is that collectives need not have an overall, monistic purpose. Accepting that they must have a single goal is what motivates the mistaken view that we are complicit for whatever occurs in a system in which we participate. The 'collective' is thought to have a single, overarching purpose, which all participants are contributing towards, regardless of whether they will it. This overarching goal of the collective is then imputed to individuals to find them complicit for it, or at least in instances where it is morally problematic.

Here, it is important to make a clarification. In denying that they are monistic, my contention is not that collective endeavors often have plural goals, but rather that the collective need have no goals at all. What is plural are its uses by agents who themselves are the source of plural projects. The collective, in other words, is simply the occasion that facilitates them.

The second feature of the account I am offering is that it allows for "modularity" within a collective endeavor. By modularity, I mean that agents are not responsible for

the distinct ends served by a collective endeavor (which is entirely a function of the way individuals choose to use it), simply by entering the joint endeavor and providing the occasion for it.

I submit that this second feature, which roots culpability for abhorrent action taken on behalf of a collective entity, in individuals, avoids a key conceptual error. What I have in mind can be framed as the converse of Kutz's "I-We" problem, what I will call the "You-I" problem. By giving some sort of overarching purpose to a collective, we ascribe to it a goal that some will find morally problematic. Thus, when the system is used for this morally problematic end by certain individual's autonomous actions (for their own projects), it is then ascribed to uninvolved persons in order to find them complicit. As I have said, this error only occurs if we regard the collective as having some sort of overarching goal rather than simply facilitating the plurality of goals for which individuals will use it.

The key upshot of this, which I have faintly gestured at already, is that we are not complicit for the ways in which our contributions to an amoral marketplace are used or misused by others of their own volition³. Here, I am appealing to the notion that there cannot be straightforward links of moral responsibility drawn between individuals simply because they serve as a 'but for' cause of another person's wrongdoing in collective participation. This is because the voluntary action of other individuals acting in full knowledge, and without coercion, breaks the chain of responsibility via autonomous action by another agent⁴. For example, if a pharmacist dispenses drugs to a sick patient with a prescription, who instead of using the drugs to treat her ailment, decides to use it to create a lethal cocktail for a victim, the pharmacist is not thereby responsible.

In the language of the conceptual framework we have assembled, this can be said as follows: the pharmacist acted in accordance with his role in dispensing drugs for which there is a valid prescription and medical diagnosis. Thus, his motivation for supplying the drugs is in accordance with his professional duties. The patient's project of harming another individual is made possible by this, namely by receiving the prescription dispensed by the pharmacist, but for an entirely different purpose. Given that the pharmacist did not act in a way that impaired the ability of the patient to act voluntarily, and did not share in her objective, she is not complicit in the act, done entirely of the latter's own volition.

VIII. A Revised Account of Collective Complicity

These findings in mind, I now move to offering my positive account of collective complicity. Though it retains

3. This example only works *ceteris paribus*; it assumes of course that the pharmacist had no knowledge of the patient's horrible intentions, and could not reasonably have been expected to know. Also, I have avoided the use of the oft-cited "arms dealer" scenario, in which an arms dealer selling guns to an agent intending to commit a robbery is used to probe the question of whether she would be complicit. I think the arms dealer example evokes emotional associations with guns that it would be best to avoid for a fair understanding of the relevant moral issues at stake here. I hope that the pharmacist example animates the same concerns.

4. In complicity doctrine in criminal law, this is often called *modus actus interveniens*.

Complicity and the Collective in the light of Physician Aid-in Dying

some features of Kutz's account, I make important revisions to resist the shortcomings I have highlighted above. We have seen that Kutz's account suffers from its monistic assumption that collective endeavors have an overarching goal, which, if result in wrong or problematic outcomes, allows us to impute complicity to individuals who do not deserve it. This is problematic because it produces the false result of finding individuals who simply participate in a collective endeavor, but do not use it for the same ends as those who are culpable, to be complicit.

The goal of my revised account is thus twofold. The first is to preserve the Kutz's framework insofar it finds individuals complicit for their participation in collective outcomes in which participants will only one possible outcome. The other is to offer an explanation of the way in which individuals within non-monistic collective endeavors, despite their modularity, can be held complicit if their acts of will align with others in the collective by facilitating the same projects.

As we have seen above, the upshot of following the monistic assumption in cases where no straightforwardly singular goal can be ascribed to the collective is that some individuals have unrelated uses of the collective imputed to them. Thus, those who are complicit in non-monistic collective endeavors will the same morally impermissible use of the collective in service of a shared end. Revisiting the example of the pharmacist, if she was party to the act of killing the victim with the drugs sanctioned by the prescription, by willing his death, this would render her complicit. This is because a willing agent is utilizing the collective, in this case a healthcare regime, in the service of this end.

The difference then, is that in the original formulation of the example, the pharmacist was simply providing the prescribed medicine, and the intervening acts of will, altering the ways in which it was used by the perpetrator, broke the chain of complicity.

In this case, she wills the same morally impermissible project for the collective, and thus her use is not modular in the relevant sense. This example can be used to assemble a new principle for complicity in collective endeavors, The Revised Complicity Principle (RCP). This can be captured as follows:

I am complicit in what others do when I will the same morally impermissible, collective-dependent end, and our projects overlap non-accidentally.

The last qualification is important, for reasons that may already be apparent. As we have seen, we often provide the conditions of possibility for others impermissible uses of collective endeavors simply by executing our roles in them. If we do this because we share in the project (in this case an impermissible one), we are then complicit, as the overlap in the collective is non-accidental, and modularity is not present. Rather than being orthogonal, our projects cut across each other. This is precisely the notion we explored with the pharmacist above.

This observation generalizes to similar types of

collective endeavors. As Hume pointed out about property, the corporation, language, healthcare regimes, and other examples in this vein, are all artifices (Hume 2000). Their existence is entirely a function of the fact that others understand the appropriate conventions and the terms of engagement with these conventions. In the case of property, Hume notes that the convention of abstaining from simply taking the possessions of others ensures that this artifice achieves a sort of "stability" that allows it to be efficiently used by individuals (Hume 2000).

To put it differently, this means that the convention simply supplies the occasion for individual projects to be pursued. We benefit when others abide by the convention to establish a collective, which in turn makes what would otherwise be difficult to achieve, attainable in a less cumbersome fashion.

Our uses of property are "modular," to put it in the terms deployed earlier. My use of property for a morally problematic purpose does not thereby condemn any other individual who is merely following the conventions associated with property and thus participating in this collective endeavor. For instance, if I use a car I own to commit a murder by running over someone, it is the purposes for which I am using the artifice, namely property, that is problematic, rather than the artifice itself.

We would be making a nonsensical conceptual error, if, in order to find someone completely uninvolved in this murderous episode to be complicit, we were to impute 'violent murder' to be a goal of property in an overarching sense⁵. This is precisely the type of error that would lead to the "You-I" problem, whereby we find individuals culpable for actions made possible in a collective, though they only have modular connections with the former.

IX. The RCP applied to conscientious objection to PAD

These thoughts in mind, let me return to our prior discussion of conscientious objection to PAD. Some conscientious objectors have contended that any positive requirement on them to participate in PAD in any form is morally impermissible, given that it would render them complicit. However, I submit that what has been said above sheds some light on the veracity of this claim, and ultimately finds it to be unfounded. We can illustrate this with the example of referral, which has drawn resistance from conscientiously objecting physicians.

When providing a referral, a physician's end (even one that has a conscientious objection) is ensuring patient access to a legally available service. The means to both ends overlap accidentally; the physician need not (and practically speaking, could not) will all the goals that his act or providing a referral could serve to facilitate (Hume 2000). She certainly provides the means to assisted death, but need not endorse its end (Hume 2000). This in other words, is the 'amoral marketplace' Kutz touches on above. The physician's and patient's different moral projects are pursued independently of each other, except

5. I am not suggesting that Kutz would be committed to this characterization of complicity in the property example, only that monistic assumptions, by analogy, can lead to these absurd consequences.

for an amoral overlap in a healthcare regime that happens to be the occasion for both their projects⁶.

This point of contact between the endeavors of both agents (physician and patient requesting PAD) is morally neutral precisely because it is the independent action of the patient after receiving the referral that breaks the chain of complicity that the conscientious objector worries about. The referral does not literally drag the patient to the willing provider; the patient will still have a series of deliberations before and after consulting the latter, and at the very least exercises some of her own agency in deciding to go through with the appointment provided by the referral.

Underlying this claim is the earlier, brief discussion of reasonable pluralism. We cannot police the uses of our contributions to a system if we accept that others have the capacity to structure their actions in accordance with their comprehensive doctrines. This is the realm of moral freedom a liberal regime works to ensure.

Moreover, we cannot frame our discussions of complicity by imputing a morally problematic goal to certain types of collectives, such as a healthcare regime, and then work backwards from this assumption to condemn individuals. In this vein, if, as conscientious objectors, we demand that all uses of a healthcare regime harmonize with our own moral commitments, we are attempting to reframe what is itself the possibility for diverse projects, to have a single, monistic goal that we must all thereby assent to.

X. Conclusion

There are lessons of a wider breadth to be drawn from our investigation here. Animating my claims have been the earlier, brief discussion of reasonable pluralism. We cannot police the uses of our contributions to a collective if we accept that others have the capacity to structure their actions in accordance with their comprehensive doctrines. This is the realm of moral freedom a liberal regime works to ensure. Moreover, we cannot frame our discussions of complicity by imputing a morally problematic goal to certain types of collectives, and then work backwards from this assumption to condemn individuals.

This type of move is all too tempting, but must be resisted. Given the vivid examples of joint action resulting in deplorable outcomes that are at our fingertips, whether from corporations, states, or organizations of crime and terror,

6. My claim that healthcare regimes can be amoral marketplaces might appear at odds with the fact that professional societies associated with healthcare systems, such as the American Medical Association, routinely take normative positions on substantive issues. Further still, institutions such as hospitals may have religious affiliations that imply particular stances on issues of moral significance such as abortion and indeed physician-aid-in-dying itself. However, my claim about health care regimes being amoral marketplaces (provided they meet the requirements of not being monistic and featuring modular activity) is not undermined by the existence of professional organization's ethically substantive codes of conduct or indeed religiously affiliated hospitals. This is because my claim does not preclude the possibility that individuals will regard their roles in a healthcare system as morally freighted. My point is simply that no one individual can claim that their particular moral beliefs translate to being the only legitimate understanding of the goals of a healthcare system. No agent in the system, or indeed an organization representing a collection of them, enjoys a monopoly in this sense.

finding individuals complicit by imputing an overarching, singular goal to collectives is a tantalizing prospect. As we have seen with Christopher Kutz's account, and others in this vein, conflating participation in the conditions of possibility for our private projects, with a pernicious purpose itself, can be an easy way to overcome the difficult problem of ascribing complicity in collectives. Its ease however, is a strong indication that it is a careless move.

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Article

The Public Health Ethics of Modern Quarantine: Lessons from the Ebola Crisis

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The 2014 Ebola Crisis culminated in an unprecedented public health emergency for local, national, and international actors on a global scale. Though several public health interventions were implemented to control the growing epidemic, the most controversial strategy was the use of mass quarantine – or cordon sanitaire – of entire communities in the affected countries of Guinea, Sierra Leone, and Liberia. Though a plethora of factors, including political and economic context, must be considered in public health decisions for the control of Ebola, ethics must be a central concern in order to find an intervention that balances respect of individual liberties with protection of the common good. This paper applies an ethical framework for public health interventions, put forth by Professor Nancy Kass of John Hopkins School of Public Health, in order to conduct a retrospective ethical analysis of cordon sanitaire for the control of Ebola Virus Disease (EVD). Structured around Kass' six questions for assessing the efficacy of any public health interventions, this paper seeks to assess the extent to which cordon sanitaire was an effective intervention for advancing public health goals while maximizing individual liberties and furthering social justice. This paper also assesses the potential efficacy of other public health interventions that were not implemented during the 2014 EVD outbreak. The application of the public health framework ultimately provides valuable insight on the extent to which the modern use of mass quarantine is an ethical public health intervention for the control of EVD going forward.

Introduction

The most recent outbreak of Ebola virus disease (EVD) in West Africa, reported to the World Health Organization (WHO) in March 2014, was the largest and deadliest outbreak of Ebola since the first appearance of the virus in 1976, with more cases and deaths than all other outbreaks combined (World Health Organization 2015). This outbreak was indeed unprecedented not only in how quickly it spread between the affected countries of Guinea, Sierra Leone, and Liberia, but also in the severity of the public health response that was ultimately mounted to address the crisis. Employing an intervention that was first developed for the control of the bubonic plague in the 14th century and last used in the early 20th century for the control of typhus across the Russian border, the governments of Guinea, Sierra Leone and Liberia announced plans in August 2014 to impose military-enforced mass quarantines — or cordon sanitaires — of entire communities, both urban and rural, in an effort to control the spread of the disease (McNeil 2014, Agence France-Presse 2014). This response to the 2014 Ebola crisis currently stands as the only modern example of mass quarantine as a public health intervention to control the spread of disease, and therefore presents crucial lessons surrounding the use of mass quarantine as a public health intervention in the 21st century. Indeed, the response to the Ebola Crisis deserves a thorough ethical analysis in order to investigate the strengths and weaknesses of modern cordon sanitaire as a public health intervention, as well as to ultimately assess whether it is a

necessary, effective, and ethical strategy for the containment of Ebola virus disease in the future.

Furthermore, considerations from the Ebola quarantine may prove integral for future strategies for the control of epidemics in West Africa. This concern is particularly pertinent in the wake of the Ebola Crisis, as the emergency concerns of Ebola led to significant disruptions in other health efforts, such as vaccination campaigns. A study conducted by the Médecins Sans Frontières (MSF) in the slums of Monrovia, Liberia's capital city, revealed a fall in measles immunizations by 75% as a result of the Ebola Crisis and predicted up to 16,000 measles deaths due to disruptions in healthcare facilities caused by the Ebola epidemic (Bora 2015). Though no evidence points to a significant increase in measles or other infectious disease outbreak as of yet, West Africa stands in a precarious position, and public health strategies must be devised in the event that similar crises should occur.

In order to investigate the necessity of the public health response to the Ebola Crisis, it is first imperative to understand the factors that facilitated the unprecedented severity of the 2014 EVD outbreak. There were several determinants that allowed for this outbreak to spiral into a full blown epidemic, including recent civil conflict, population growth, widespread poverty and the highly interconnected populations of Guinea, Sierra Leone, and Liberia (Sun et al. 2014). However, these factors, while they facilitated the spread of the infection, did not mean that the epidemic was inevitable (WHO Ebola Response Team

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2014). Previous EVD outbreaks have proven the effectiveness of early control measures when implemented within 2-3 weeks after the introduction of the disease (WHO Ebola Response Team 2014, Borchert et al. 2011). In past outbreaks, teams of foreign health experts, generally from Europe and the United States, have recruited local health workers and used public health tactics such as contact tracing, safe burial practices, and isolation and care of known victims to contain the outbreak to rural areas (McNeil 2014, Alexander et al. 2015).

However, in the case of the 2014 EVD outbreak, local health services were quickly overwhelmed and the international public health response lagged months behind. Although the first cases were reported to the WHO in March 2014, the WHO only began to set up operation centers to oversee the support for affected countries in July 2014 (Medecins Sans Frontières 2015). Response severely lagged at the level of the affected national governments as well, as Guinean President Alpha Conde has since been heavily criticized for calling the Ebola outbreak “under control” during a visit to the WHO headquarters in April 2014 (Medecins Sans Frontières 2015, The Washington Post 2014). The lag in public health response and unique challenges of Ebola in West Africa allowed the 2014 outbreak to spread to densely populated urban areas, confronting public health officials with a situation never before encountered for the control of Ebola. Public health measures that had been employed in the past were ultimately deemed insufficient to control the spread of the disease, resulting in the turn to cordon sanitaire as the primary strategy.

Nancy Kass, a professor of Bioethics and Public Health at John Hopkins School of Public Health, offers a fitting framework for an assessment of the quarantine measures implemented in Sierra Leone, Guinea and Liberia. Her public health ethics framework presents six questions that are geared towards the assessment of public health interventions specifically. This framework is therefore more apt for the assessment of the Ebola Crisis than several other available frameworks, as the 2014 outbreak was fundamentally a public health crisis. These six questions are meant to illuminate the most effective interventions for advancing public health goals while maximizing individual liberties and furthering social justice. This framework is structured to offer practical guidance for public health officials to assess the ethicality of any proposed public health intervention. Though this is a retrospective analysis rather than a hypothetical consideration, the application of this framework will highlight the strengths and weaknesses of quarantine in the context of Ebola in West Africa and will provide valuable insight on the extent to which the modern use of quarantine is an ethical public health intervention going forward.

1. What are the public health goals of the proposed program?

The fundamental goal, Kass asserts, of any proposed public health program is the reduction of morbidity and mortality. She writes that, although more direct goals pertaining to health and social benefits may be addressed, the reduction of morbidity and mortality is the outcome by which any program must ultimately be assessed. While certain programs, such as research studies and clinical trials in developing nations, are more convoluted in terms

of this ultimate goal, quarantine is quite straightforward. The objective of quarantine, whether at the individual, household, or community level, is to reduce transmission of infectious disease and thus reduce morbidity and mortality. However, an important consideration discussed in this framework is to whom this goal is directed towards. The conundrum of many public health interventions is that they often target one population in order to protect the health of another population. While public health interventions, such as quarantine in this EVD outbreak, intend to protect the wellbeing of the general population, and thus may restrict individual rights for the sake of the greater population, it must not be done at the expense of the basic rights of those under quarantine.

This has historically been a primary concern with cordon sanitaire — a line is drawn around an affected community and no one is allowed out, not only exposing individuals inside the

“ Increased transmission of the disease within cordoned areas coupled with increased reports of quarantine violations point to an overall ineffectiveness of the imposed area quarantine in addressing the ultimate goal of decreased morbidity and mortality.”

cordon to the infectious disease, but limiting their access to food, water, and other basic necessities (Rothstein 2015, Hoffman and Hoffman 2015).

For the 2014 EVD outbreak, the protection of the rights of those under cordon was a clear concern on the international level. The WHO and CDC declared that, while they were not opposed to the implementation of a cordon, it would need to respect the human rights of those within the cordon in order to be considered ethical (Hoffman and Hoffman 2015). The international response attempted to incorporate protection of those cordoned into the goals of the quarantine, as they worked closely with the United Nations World Food Programme (WFP) to coordinate efforts to supply quarantined zones with food and other non-medical supplies (World Health Organization (a) 2014). Thus, the strategy of cordon sanitaire that was declared in light of the Ebola Crisis was both aimed towards decreasing morbidity and mortality and, at least at the international level, considered the protection of individual rights within the cordon. However, the effectiveness of these stated public health goals is much less clear, a concern that is addressed in the second question of the public health framework.

2. How effective is the program in achieving its stated goals?

In this section of the framework, Kass asserts that public health interventions are based on the assumption that the proposed action will be effective in reaching the stated goals of the program. As discussed in the section above, the ultimate goal of mass quarantine in the Ebola crisis was to reduce morbidity and mortality from the disease – to control the spread of the disease.

Kass stresses that there must be data to support that these assumptions will amount to an effective method in achieving the program's goals. Furthermore, the greater the social and economic costs of the program, the stronger the evidence must be that it will be effective. This is an incredibly pertinent discussion to the use of large scale quarantine for control of EVD transmission.

Quarantine, as opposed to other social distancing measures to limit close contact (such as isolation of known infected persons), is based on the assumption that asymptomatic people may be infectious and may expose others to the disease (Rothstein 2015). While this is a reasonable assumption to make for airborne diseases, such as influenza and SARS, it is not a reasonable assumption to make in the case of Ebola. Ebola transmission occurs by contact with highly infectious bodily fluid, primarily the vomit, diarrhea and blood of individuals who have become seriously ill from the virus (Rothstein 2015). This means that asymptomatic individuals, and even those in the earliest stage of infection, whose primary symptom is fever, are not infectious (Chertow et al. 2014). Furthermore, while data in the past have indicated the effectiveness of area quarantine in containing infectious disease, there was no quantitative evidence that it was an effective strategy for the control of Ebola (Rothstein 2015, ACAPS 2015). In fact, a retrospective study found that, for Liberia and Guinea, the number of new cases rose exponentially around the time that the cordons were first imposed (Towers et al. 2014). That said, this period of time also coincided with an increased global response to the crisis and therefore increased surveillance could account for some increase in reported case numbers; however, given the history of cordons to increase the spread of disease within the cordoned area, there is significant evidence that area quarantine for Ebola contributed to increased transmission of the disease (Towers et al. 2014, Adalja 2014).

In addition to cordon sanitaire's lack of effectiveness in achieving its stated goal, it violates the fundamental human rights of those under quarantine. Despite international efforts to protect the rights of those impacted by the cordons, the actual measures implemented in Guinea, Liberia, and Sierra Leone demonstrated a clear disconnect from the statements released by the WHO and CDC regarding protection of human rights for those under quarantine. Soon after the cordon was imposed in Liberia, essential goods such as food and water doubled in price (Onishi 2014). Residents of the quarantined West Point slum reported that the quarantine prevented them from accessing basic necessities and from being able to leave the area in order to work (Hoffman and Hoffman 2015). These problems also characterized cordons implemented in rural areas, where many households did not

receive food packages until 24-48 hours after being placed under quarantine due to poor coordination at the local level and lack of road access (ACAPS 2015). The lack of effective provision of basic necessities to those under quarantine was not only unethical in that it did not protect the basic human rights of these individuals, but also led to behaviors that could increase transmission of the disease, as there were several reports of slum residents violating quarantine in search of basic provisions (ACAPS 2015). Increased transmission of the disease within cordoned areas coupled with increased reports of quarantine violations point to an overall ineffectiveness of the imposed area quarantine in addressing the ultimate goal of decreased morbidity and mortality.

“Of all of the social distancing measures that may be implemented to limit close contact during an infectious disease outbreak, such as isolation or shelter-in-place, quarantine is by far the most intrusive on individual rights for the sake of protecting the health of the greater population (Rothstein 2015).”

Perhaps the facet of this discussion that speaks most emphatically against the effectiveness of area quarantine for control of Ebola is the fact that one of the most important assumptions for the effectiveness of quarantine, that asymptomatic individuals have the ability to transmit the diseases, does not actually pertain to the transmission of Ebola. The other inefficiencies of the cordons speak to a lack of experience rather than a lack of due consideration of the facts. Besides the SARS outbreak of 2003 in Southeast Asia, the EVD outbreak of 2014 marked the first time that large scale quarantine was implemented since the first half of the 20th century (Rothstein 2015). While there was a relative lack of data regarding how effective quarantine would be for control of the disease, it is important to recognize that this was an emergency response to an unprecedented situation and thus no data was available for actors at the international, governmental or local levels. Government actors learned along the way and modified quarantine policies in accordance with public response. Ultimately, the quarantine measures still offer valuable lessons to be gleaned for the control of Ebola and large infectious disease outbreaks in West Africa.

3. What are the known or potential burdens of this program?

This section of the public health framework turns to

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identifying the known ethical burdens of a public health intervention (Kass 2001). Of all of the social distancing measures that may be implemented to limit close contact during an infectious disease outbreak, such as isolation or shelter-in-place, quarantine is by far the most intrusive on individual rights for the sake of protecting the health of the greater population (Rothstein 2015). Therefore, it raises a great deal of burdens that must be considered and addressed in order to ensure that it is implemented ethically.

First of all, quarantine poses significant risks to liberty and self-determination. If the individual needs and rights of those within the cordoned areas are not adequately addressed, the use of quarantine becomes ethically questionable. One particular burden for cordon in West Africa is the severe restriction on movement, as the nations of Guinea, Sierra Leone and Liberia have highly mobile populations. In these countries, many individuals must migrate in order to conduct trade or to find work, particularly agricultural workers whose work changes on a seasonal basis (Roos 2014). The strict restriction on movement imposed in Liberia sparked violent clashes between security forces and the residents under quarantine, where live ammunition was used and dozens were injured (ACAPS 2015).

Due consideration of the burden of restricted movement is necessary for ethical cordons. The inability of many people to make a living under the restrictions on movement, coupled with the spike in food prices due to decreased trade under the condition of restricted movement, also makes food security a primary burden that must be addressed by international and national government actors. Access to basic resources, such as water, and adequate sanitation for those within the cordon are burdens that must be addressed. Access to resources for adequate sanitation is a concern particularly in urban slums where public latrines are often shared amongst many members of the community (ACAPS 2015).

Another fundamental burden of quarantine that must be considered is the social stigma surrounding Ebola in West Africa. Ebola is often associated with shame and, since quarantine can associate many individuals with the disease, it can significantly change the social landscape of the lives of those who are quarantined (ACAPS 2015). Individuals, households, and even communities placed under quarantine are susceptible to stigmatization and ostracism, a fact that is particularly burdensome for quarantine given that it is placed on individuals who are asymptomatic and, of the way in which Ebola is transmitted, not actually infectious (Ebola Response Anthropology Platform 2014). Social stigmatization is a powerful social determinant of health, and thus quarantine poses a significant threat to justice when this stigma is imposed disproportionately on a single community (Hatzenbuehler et al. 2013).

4. Can burdens be minimized? Are there alternative approaches?

Once the burdens of a public health program have been identified, there is an ethical obligation to consider whether this program could be modified in order to minimize the burdens while not greatly reducing the program's efficacy (Kass 2001). The most important measure that must be

taken to minimize the burden of cordon sanitaire is the timely delivery of resources to cordoned areas. This is not only ethically imperative to protect the basic human rights of those under quarantine, but an important measure to increase public trust in the necessity for quarantine and to decrease quarantine violations.

Another aspect that could be mitigated in the cordon is the restriction of movement for those under quarantine. One way to minimize this burden is relaxation of night-time curfews within the cordon. This was demonstrated to increase compliance in the West Point slum when the Liberian government decided to relax its night-time curfew in response to the violence that erupted between residents and security forces (ACAPS 2015). Furthermore, restrictions on movement in and out of the cordon could also be relaxed. While this would seem to reduce the efficacy of the cordon, the reality of the matter is that a complete quarantine of every potentially exposed individual is not scientifically necessary to control transmission of the disease (Rothstein 2015). A "leaky quarantine" that allows increased movement in and out of the affected area can still be effective for decreasing transmission, as it can slow the number of new infections to below the total number of deaths plus the total number of people who have recovered (Matthews et al. 2009). Furthermore, relaxation on movement in and out of quarantined areas would better facilitate the timely delivery of services to those under quarantine, which would in turn have a significant impact on compliance and protection of individual rights and social justice in the context of quarantine.

Finally, the burden of stigmatization must be mitigated by an improved mechanism for dissemination of information in order to change cultural understanding surrounding the spread of Ebola. An Oxfam protection assessment released in March 2015 revealed persistent stigmatization of individuals associated with Ebola by community and religious leaders (ACAPS 2015). Continued efforts to reduce stigmatization must effectively target community and religious leaders, as understanding amongst these leaders is crucial for improving social conditions within cordoned areas (ACAPS 2015).

While the above measures are crucial for minimizing the burdens of cordon sanitaire and increasing its efficacy, the second part of this section asks whether there are alternative approaches to the same goal that may be equally effective. Kass explains that, if two options exist to address a public health problem, there is an ethical obligation to choose the approach that poses fewer risks to moral claims, such as liberty, privacy, opportunity and justice.

One such alternative approach that has been proven to be effective is voluntary, or self-imposed, quarantine at the community level (Rothstein 2015, ACAPS 2015). It was demonstrated in Liberia that the most effective method for minimizing quarantine violations and maintaining a positive relationship with quarantined communities was the orchestration of the effort by local and religious leaders rather than by the national government (ACAPS 2015). Admittedly, this approach runs the risk of lacking efficacy, as there have been reports of local community members denying quarantined individuals access to water and to basic

provisions; however, increased communication of district and national level authorities with community leaders proved to mitigate these risks (ACAPS 2015).

Furthermore, another consideration that must be made is whether quarantine of any kind is the most effective social distancing measure for the control of Ebola, especially given how burdensome it is to individual rights and social justice. As discussed earlier in this paper, it is not scientifically clear that quarantine is the most effective way to decrease transmission of this disease. Because of the way in which Ebola is transmitted, the escalation of the epidemic was largely due to a lack of personal protective equipment and functioning hospitals, which led to a disproportional infection rate amongst healthcare workers and untrained family caregivers treating patients who were severely ill and therefore highly infectious (Rothstein 2015). A study conducted in Sierra Leone found the incidence of Ebola to be 103 times higher for caregivers than for the general population (Kilmarx et al. 2014). Because of the decreased accessibility of resources in quarantined areas, cordons stifle the distribution of personal protective equipment and inhibit trained personnel from effectively treating patients in cordoned areas before they reach the infectious stage of the disease (Rothstein 2015). Therefore, a shift in focus to isolation and treatment of those exhibiting the non-infectious fever stage of EVD may prove to be an entirely more effective and less intrusive social distancing measure than quarantine of non-infectious individuals. Such efforts would have to be coordinated and standardized at the level of international and national governments to be both safe and effective, as there were several instances during the Ebola Crisis of community members setting up informal isolation centers and isolating other community members without appropriate protection (Gettleman 2014). Ultimately, there are several ways that the burdens of quarantine could be mitigated for the control of Ebola, but they must be done so in a strategic manner in order to be effective.

5. Is the program implemented fairly?

The fifth section of the public health framework turns to the consideration of distributive justice, asserting that identified benefits and burdens of an ethical program must be fairly distributed. This does not mean that they have to be equally distributed, but rather, that unequal distributions must be justified with data. For this section, the analysis of the use of area quarantine must be investigated on a global scale. Is it fair to subject a single population, in this case the citizens of Guinea, Sierra Leone and Liberia, to widespread cordon sanitaire for the sake of reducing global transmission of the disease? The answer, in theory, is yes.

Public health officials have a responsibility to protect and promote population health, even at the expense of restrictions on individual autonomy. If the proposed intervention has been demonstrated to be effective in reducing transmission with data and the basic rights of those in cordoned areas are adequately protected, then public health officials on an international and national government level have an obligation to protect the greater population by implementing an effective cordon to control the spread of infectious disease. That said, evidence from retrospective analyses of cordon

sanitaire in the Ebola Crisis in 2014 point to the fact that it was neither effective in reducing morbidity and mortality nor effective in protecting the rights of quarantined individuals. In fact, data released by the WHO demonstrates a stark increase in case counts over the period that cordons were implemented in Guinea, Sierra Leone and Liberia in August to the time that restrictions were eased in October (World Health Organization 2014 (b), Enserink 2014). Ultimately, there is insufficient data supporting the effectiveness of cordon sanitaire in protecting public health to justify such an uneven distribution of burden to cordoned communities in West Africa.

6. How can the burdens and benefits be fairly balanced?

The final question of the public health ethical framework concerns balance — do the expected benefits justify the expected burdens? When it comes to quarantine, this essentially boils down to a balance between the benefit to public good and the burden to individual liberties. Ultimately, as we have seen from the retrospective analysis of the use of cordon sanitaire during the Ebola Crisis in West Africa, quarantine is an incredibly strict measure on individual liberties that lacks a fair distribution of benefit and burden. On the other hand, however, there are many public health measures that, while more fair in distribution of benefit and burden, are ineffective for handling an emergency situation such as the 2014 EVD outbreak.

For instance, before quarantine was implemented, several affected states invoked stay-at-home days for “reflection, education and prayers” and closed all educational institutions (Gostin 2014). These measures were not appropriate given the need for the implementation of swift and effective public health control measures. Thus, the benefits and burdens for the control of Ebola in West Africa could have best been balanced by a technique somewhere in between these two extremes, namely an effective isolation and treatment strategy along with the implementation of self-imposed quarantine. The development of an effective isolation and treatment public health strategy for the control of Ebola in West Africa going forward would likely be effective given the way in which Ebola is transmitted. Furthermore, the implementation of voluntary quarantine, along with education of religious and community leaders in order to reduce stigma and increase compliance, presents an ethical strategy for balancing the public good and individual rights of immediately affected communities.

Conclusion

Ultimately, a plethora of factors other than ethical concerns are considered when making public health decisions; however, ethics still must be fundamental to public health interventions in order to strike the necessary balance between protecting the common good and respecting individual liberties. This balance is particularly crucial for the consideration of modern quarantine, as it is a tool that has immediate and far-reaching consequences on a global scale. The ethics framework for public health put forward by Nancy Kass presents rigorous criteria that reveal the myriad of considerations that must be taken into account for the implementation of quarantine for the control of Ebola

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virus disease in West Africa, such as protection of individual liberties and the conditions of distributive justice.

From this analysis, it is abundantly clear that area quarantine pales in both effectiveness and ethicality to other social distancing measures when it comes to dealing with Ebola. However, it must be recognized that Kass' framework, while strong in its consideration of the ideal balance of both effectiveness and ethicality, has its own limitations. Perhaps the largest limitation of this framework is a lack of consideration for feasibility within particular economic and political contexts. For this analysis, this oversight is most applicable to our consideration of alternative approaches, as the framework does not offer a consideration of the feasibility of alternative approaches, only a consideration of the balance between the protection of individual liberties and overall effectiveness.

Despite the limited consideration of feasibility of alternative approaches than area quarantine, this analysis shows strong evidence for both a greater effectiveness and protection of individual liberties in an isolation and treatment strategy. Priorities in an infectious disease outbreak such as Ebola should therefore shift away from quarantine, which tends to cut off essential supplies to the most affected areas, and instead towards a rigorous isolation and treatment strategy, accompanied by voluntary quarantine by affected communities. Early recognition of the disease and coordination of these interventions at the international, national, and community level will be crucial for the effectiveness of these measures. The Ebola Crisis was not the first outbreak of EVD and is most certainly not going to be the last. It is imperative that public health officials learn from the unprecedented emergency experience of the 2014 Ebola outbreak in order to strategize should a crisis of such magnitude arise in the future. Of course, several measures have been implemented in an attempt to prevent future outbreaks from reaching the same level of emergency, including the establishment of country offices in Guinea, Liberia and Sierra Leone by the CDC to help identify, prepare for, and mitigate future outbreaks (Dahl et al. 2016).

However, the same has not been done to prepare an effective, ethical emergency strategy in the case that an outbreak reaches the same point despite these preventative efforts. This is particularly alarming given the fact that it is exactly in such situations of crisis that human rights and social justice are in need of the strongest protection afforded by available public health interventions. Therefore, future considerations for the control of Ebola from a public health perspective must incorporate the lessons learned from the 2014 Ebola outbreak in order to effectively control the spread of disease while protecting individual liberties and maximizing social and distributive justice.

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