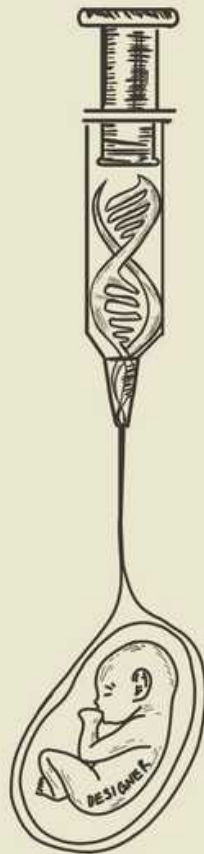




C U B E

C U Bioethics



1ST EDITION

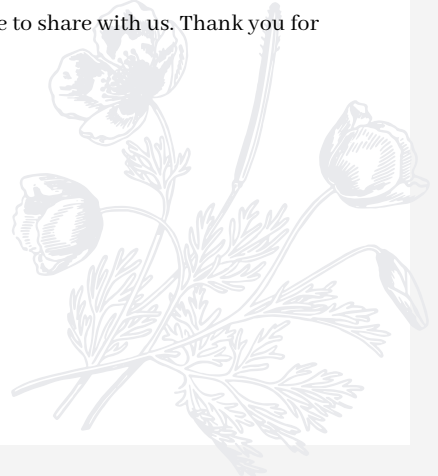
ABORTION - EUTHANASIA - GENE EDITING - END OF LIFE CARE - AI ETHICS -
MENTAL HEALTH CARE - VACCINE HESITANCY - INFECTIOUS DISEASE

Editor's Note

We are delighted to introduce CUBE, the first Bioethics Newsletter at the Chinese University of Hong Kong. CUBE – an abbreviation for CU Bioethics – is also a reference to the multifaceted nature and philosophy of real life ethics. We hope the magazine provides a free space for writers and readers alike to explore the expansive multidisciplinary realm of ethics, and the contemporary implications of medical procedures, technologies and treatments. As an amalgamation of student insights and opinions, our Newsletter aims to invite thought-provoking conversations.

The modern world's trajectory – marked by globalization, technological development and other evolutions – is constantly advancing and likewise are the bioethical discussions we have on a daily basis. This edition of the Newsletter will feature a collection of student-written articles dissecting the ethics of a variety of topics, from euthanasia and genome editing to eating disorders and human infectious studies.

We hope this Newsletter will serve as a portal to an enhanced understanding of the medical world, encourage introspection, and prompt a (re)examination of a myriad of intersections between healthcare and the humanities. Therefore, we believe this Newsletter is for everyone. We welcome you to start a conversation with us about anything we have shared or anything you would like to share with us. Thank you for reading and for being a part of this conversation.



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The Tug-of-war on Female Autonomy

Hei Man Kwok Y/4

In the march towards Sexual and Reproductive Health and Rights under the Universal Healthcare umbrella Universal Health Coverage (UHC) was getting everyone's attention this May at the 72nd World Health Assembly (WHA72). From the collaborative discussions about implementation of Primary Health Care (PHC) to the congratulations over the successful inclusion of air pollution as a fifth non-communicable disease risk factor – one topic remained especially controversial at the annual congregation of 194 World Health Organization (WHO) member states and non-state actors, namely, the topic of Sexual and Reproductive Health Rights (SRHR).



*"You cannot have maternal health without reproductive health. And reproductive health includes contraception and family planning and access to legal, safe abortion."
~ Hillary Clinton*

It has been two years since the outspoken President Trump and Vice-President Pence took office, and their calls for restrictions on the provision of SRHR healthcare are alarming to global health enthusiasts. With their pro-life stance, Pence's bid to ban abortions in Indiana [1], and the attempts to defund Planned Parenthood, the landscape for SRHR in America looks worrying to many. Coupled with challenges to the landmark Roe v. Wade decision in 1973, the right to abortion in America appears to be sitting on a wobbling pedestal. As the tug-of-war between the pro-choice and pro-life camps appears to have no end in sight, let's examine the ethics behind the question of "when does life begin?" and by extension, "when does a fetus have the right of a human being?" When it comes to abortion, it's contentious and many have an opinion but even in academia, this question is still highly contested.

Sandel argues that to be considered a being, one must have sentience capable of experience and consciousness, rendering fetuses

not constituting a being [2]; while George and Lee believe that embryos are part of a continually developing human being and hence their rights should be protected. They argue that the embryo is a human being – a complete and whole organism with the genetic constitution and epigenetic primordia, the precursor of a functional brain and central nervous system for a human being [3]. But the question as to when life and the rights of the fetus begin are still unanswered, a consensus has yet to be made.

One lesson I've learnt from the WHA72 is the political nature of health. With the looming changes to the Title X (also commonly referred to as the Title X gag rule), fears that the sole federal grant program dedicated to providing information and referrals for abortions as well as contraceptives to the American public will interfere with the American public's right to reproductive healthcare [4]. As medical professionals, we must examine the ethical implications this amendment will have to our Hippocratic oaths. This new revision stipulates that if we are working in an institution which is funded by Title X, we will be obligated, by page 119, "not [to] perform, promote, refer for, or support, abortion as a method of family planning,

nor take any other affirmative action to assist a patient to secure such an abortion". This translates to not being able to offer the medical service and information about abortion to our patients, clearly violating the principle of beneficence by withholding accurate and timely medical information and may possibly interfere with the principle of non-maleficence as this pregnancy may cause the mother unnecessary physical and psychosocial stress with complications during pregnancy possibly leading to death. In my opinion, the modifications to Title X will undoubtedly restrict our ability to provide quality healthcare to patients and violate our medical ethics, and I ask, "What happened to 'first, do no harm'?".

"We have been God-like in our planned breeding of our domesticated plants and animals, but we have been rabbit-like in our unplanned breeding of ourselves."

~ Arnold J. Toynbee

Now those living outside the States may be thinking, "What has this got to do with me? I live halfway across the world!" but no, the tentacles of the United States of America often spread far and wide -- it also affects the SRHR in Mexico via the Mexico City Policy (also known as the Global Gag Rule). This policy states that for foreign non-government organizations to be eligible for US federal funding, they cannot inform the public or educate their government on the need to make safe abortions available, provide legal abortion services, or provide advice on where to get an abortion [5]. Although this is no newcomer to the scene of SRHR, its re-institution and subsequent expansion from only family planning organizations to include *all global health organizations* makes it a huge loss for SRHR with it now covering over ten billion US dollars of US aid [6].

As medical professionals, we must ask ourselves the same questions as our American colleagues – does the Mexico City Policy violate our medical ethical standards?

Ultimately, the topic of SRHR is large. We have only focused on some ethical concerns regarding abortion with the example of Title X and the Mexico City Policy. Other topics including but not limited to contraceptives and comprehensive sexual education continue to be debated not only in local settings but on the global arena such as at the WHA. With the ethics around the beginning of existence still blurry, I fall onto our oath to "first, do no harm" and sincerely propose to all medical professionals to reflect on the implications of SRHR and specifically abortion. Do your religious beliefs and personal ethics encroach upon the provision of SRHR including abortion? Where do you stand in this debate? Tweet to me @hmkheimank and let's continue the discussion!

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<https://www.politico.com/story/2016/07/mike-pence-obamacare-225590>.

2) Sandel, Michael J. "Moral Argument and Liberal Toleration: Abortion and Homosexuality." California Law Review, vol. 77, no. 3, 1989, p. 521, doi:10.2307/3480558.

3) Lee, Patrick, and Robert P George. "The Wrong of Abortion." CONTEMPORARY DEBATES IN APPLIED ETHICS, Blackwell Publishing, 2005, pp. 1–26.

4) Hasstedt, Kinsey. "Dangerous and Coercive Title X Gag Rule Released." Guttmacher Institute, 4 June 2019, <https://www.guttmacher.org/article/2019/02/dangerous-and-coercive-title-x-gag-rule-released>.

5) CBS News. "What Is the Mexico City Policy?" CBS News, CBS Interactive, 23 Jan. 2017.

<https://www.cbsnews.com/news/what-is-the-mexico-city-policy/>.

6) McBride, James. "How Does the U.S. Spend Its Foreign Aid?" Council on Foreign Relations, Council on Foreign Relations, 11 Oct. 2018, <https://www.cfr.org/backgrounder/how-does-us-spend-its-foreign-aid>.



The Separation of Conjoined Twins

Shuk Kwan Wong Y/2

The issue of separating conjoined twins has long been a controversial issue in bioethics and medicine. The first successful surgery of separation of a pair of conjoined twins was conducted in 1689 in Germany [1]. While "failed" surgeries have existed, such as the case of Jodie and Mary (whose real names are Gracie and Rose respectively) in 2000, only one twin survived after the separation surgery [2]. In this essay, this issue will be discussed in terms of autonomy, non-maleficence, and beneficence.

Firstly, in terms of autonomy, the decision to receive the separation surgery should ideally be left to the twins as the interests and harms concern them. However, conjoined twins are often too young to express their choice, and thus, deemed incapable of making such decisions. As a result, the parents are seen as the primary decision makers. Parents of conjoined twins may choose to receive the surgery because of psychological considerations [1] (e.g. saving one life is better than none), but they may not consider (or know) the choice and willingness of the twins. Therefore, the autonomy and the will of the conjoined twins may often be overlooked.

Secondly, in terms of non-maleficence, the possible negative effects on the health of the twins after the surgery should be considered. Separation surgeries can be complicated, as some body parts or organs of the conjoined twins may be shared. Therefore, this poses risks to the twins when undergoing surgeries. In the case of Marieme and Ndeye [3] – Senegalese conjoined twins who sought medical care in Cardiff – they shared only *one set* of most organs. There was great risk that both of them would not survive if they underwent the surgery, yet, would have also been in a fatal situation had they not been separated[2]. In non-emergent circumstances, it is thought to be immoral to perform the surgery, as the harms outweigh the benefits for the twins. Although the surgery may help in improving quality of life, there is a risk that the twins may suffer from deteriorating health like chronic illnesses after the surgery. There are also some cases where the weaker twin, who often possess fewer organs, has to be sacrificed for the benefit of the stronger twin [1]. However, from my perspective, when conjoined twins are born with one set of organs, they are shared and thus, should be owned and *equally valued* between them. Thus, I find it immoral to choose which one should receive more organs, as this severely harms and disadvantages the other twin.

Thirdly, in terms of beneficence, which twin might benefit most in an emergency is questionable. In emergency situations, it is essential for the twins to be separated, if not, both of them cannot survive. Doctors should always try their best to save both of them. However, is it always unethical to save the healthier one at the expense of the weaker one? What if both twins are "equally" healthy? How do we determine the parameters in which dictate the fate of one twin over the other? Indeed, it will always be an imperative that doctors should spend their effort to save at least one of them, however, this raises a serious ethical problem if the second twin is of similar health status, as it may be considered homicide [2].

Medical professionals should try their best to give medical advice that has the conjoined twins' best interests at heart. The potential harms and benefits for separation surgery must be considered. Doctors should give the whole picture of the separation surgery to the parents, such as advantages, disadvantages, necessity, urgency, and effectiveness, so that the best medical treatment can be delivered to the conjoined twins.

In conclusion, after considering autonomy, non-maleficence and beneficence, there is indeed no absolute answer on whether the separation surgery should be done on every pair of conjoined twins, as the decision always has to depend on the twins' current health conditions and urgency. I hope medical technology will be more advanced and can provide more solutions to this health problem, which have fewer negative impacts to conjoined twins, so as to reduce the suffering and health complications of the twins.

- 1) Punchak, M. (2011). Split Decisions: The Ethics of Separating Conjoined Twins. *Princeton Journal of Bioethics*. Retrieved from <https://pjb.mycpanel2.princeton.edu/wp/index.php/2011/11/05/split-decisions-the-ethics-of-separating-conjoined-twins/>
- 2) Wilkinson, D. (2019). Separation Anxiety – Should Treatment be Imposed for Conjoined Twins? *Practical Ethics*. Retrieved August 10, 2019, from <http://www.bioethics.net/2019/01/separation-anxiety-should-treatment-be-imposed-for-conjoined-twins/>
- 3) Two girls, one body - BBC News. (2019). Retrieved 10 August 2019, from https://www.bbc.co.uk/news/resources/idt-sh/Wales_conjoined_twins



Euthanasia: The Right to End One's Life

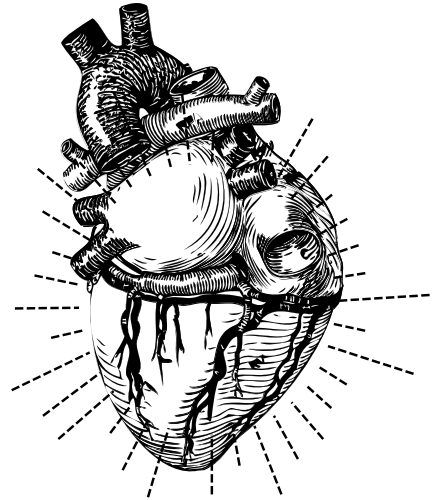
Phoenix Tam Y/5

In my rotation to the psychiatry department, I encountered a patient with major depressive disorder in Castle Peak Hospital. She was a middle-age lady with a stylish haircut and heavy make-up. She was calm and willing to talk with us, but she had just attempted suicide. She admitted that she would attempt another suicide in the future because she was in great pain. She thought that no one could understand her torment and felt that death was the only way to set herself free. She described herself as an empty body without a soul.

I can learn the symptoms of depression from medical textbooks: the patient would have symptoms such as sleep disturbance, avolition and loss of appetite. However, textbooks will never allow me to truly experience or understand her grief and pain.

Euthanasia has been a controversial issue for several decades. Most of the focus is put on patients with terminal or severe physical diseases but seldom do we discuss euthanasia for patients suffering from mental illnesses. Given the four bioethics principles of autonomy, justice, non-maleficence and beneficence; Should patients have the autonomy to end their life? Is euthanasia beneficial for patients who can no longer tolerate their mental and physical suffering?

Euthanasia is illegal in Hong Kong so some people would choose to end the life by their own way. In countries where euthanasia is legal to perform, the patients need to undergo a comprehensive assessment.



One of the criteria is that their suffering is intolerable and irreversible. The severity of physical diseases can be reflected by an array of objective parameters. On the other hand, it is difficult to quantify the degree of mental suffering as we cannot experience the feeling of another person.

We tend to face the dilemma of two or more bioethics principles in real life. By non-maleficence, the doctors should spare no pains to save patients. Under no circumstances should we do harm to our patients. However, euthanasia seems to fulfill the principles of autonomy and beneficence when the patients cannot tolerate the decline of health condition. Another problem deserving our attention is whether euthanasia can be applied to the patients with mental illnesses as competency is questionable. Therefore, euthanasia – particularly amongst mentally incapacitated patients – remains contentious.

Genome Editing in Reproductive Medicine

A look into CRISPR, Designer Babies & Eugenics

Jonathan Cheung Y/5



The CRISPR-Cas9 system offers a relatively simple 'cut and paste' method for genome editing with a high degree of fidelity with cost efficiency [1, 2]. Since its introduction as a tool for genetic engineering in less than a decade ago, it has been used in the generation of cell and animal models to mimic diseases for scientific research and the development of gene therapies for devastating diseases such as Duchenne muscular dystrophy [1, 3]. More recently, attempts to genetically engineer human embryos have also been made [4, 5], and a pair of twin girls with edited genomes was born in 2018 [6]. Such rapid progress within the field gives rise to the question of whether designer babies may become a reality.

The application of genetic engineering using the CRISPR-Cas9 system in medicine are diverse, some of which may even have the potential for breakthrough advancement towards human health. However, one of the major concerns is the use of the technology to alter human germline as this raises various ethical dilemmas [1, 7]. The aim of this article is to discuss the ethical considerations when using such a system in reproductive technology.

Should genome editing be used to prevent or eradicate a genetic disease?

A strong argument for the clinical use of CRISPR/Cas9 in modifying the human germline is the possibility of preventing or even eradicating genetic diseases. Caring for children disabled by genetic conditions can often cause significant emotional, physical and financial strains.

Therefore, the possibility of preventing suffering and having a child that would be afflicted with a disease that could significantly decrease his or her quality of life is an advantage. From a population perspective, this may lead to a healthier population with a lower demand on healthcare services.

Similar to how vaccination strategies aim to protect individuals and populations from the spread of infectious illnesses, the CRISPR/ Cas9 system could provide a similar benefit. In the era of insufficient resources wherein the demand for healthcare outweighs the supply available, the prevention of certain diseases translates into more resources being available for research and development for treatments of other diseases, such as chronic conditions that are associated with the aging population.

In the practice of assisted reproductive technology, preimplantation genetic diagnosis (PGD) allows prospective parents, who are at risk of having a child with an inherited genetic disorder, the option to have an unaffected child without having to terminate the pregnancy [8]. The use of germline gene therapy may increase the yield of 'healthy' embryos in IVF treatments for patients seeking fertility assistance due to concerns of inheritable diseases. Therefore, when used together with PGD, it could potentially increase the success rate of achieving pregnancy with healthy children, reducing the need for couples to go through multiple IVF cycles and spending more money.

Although CRISPR/Cas9 offers promising hope as a future strategy for disease prevention and treatment, it would be inappropriate to compare this advantage as being equivalent to those conferred through vaccination policies and somatic gene therapy. Safety is currently one of the biggest barriers against the use of CRISPR-Cas9 to modify the human germline. In CRISPR-Cas9 modified embryos, technical issues such as off-target mutations and mosaic embryos containing both modified and non-modified cells have been reported [4, 9, 10]. There is no knowing to what the specific off-target effect could be and whether side-effects with variable severities would be apparent from birth or develop years after birth. Thus, the risk-benefit ratio of CRISPR-Cas9 in human germline could be perceived as much higher when compared to vaccinations and somatic gene therapy. For the reasons of safety issues and principle of non-maleficence, I tend to lean against the application of the technology on human germline modification because of the unpredictability and uncertainty of side-effects that could be passed to future generations.

Furthermore, if we were to accept the application of CRISPR-Cas9 in human germline for disease prevention, could it be a slippery slope towards utilising the technology for non-therapeutic purposes, such as designer babies.

When parents start to decide on the specific traits of their future children, it would raise issues such as religious objection (playing God), actively contributing towards the selection of how our future generations should be like (eugenics) and an unjust society because it is highly likely that the poor may not be able to afford the luxury of picking the best traits for their children. Therefore the potential consequences of genetically engineered babies are not only limited to the particular family involved, but impacts on the dynamics of society as well.

In conclusion, the decision of whether human germline modification should be used in reproductive medicine requires thorough reflection and discussions on the safety of the technology, the associated long-term consequences as well as legal, moral and ethical implications.

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- 2) Ran, F.A., et al., Genome engineering using the CRISPR-Cas9 system. *Nat Protoc*, 2013. 8(11): p. 2281-2308.
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- 4) Liang, P., et al., CRISPR/Cas9-mediated gene editing in human trippronuclear zygotes. *Protein Cell*, 2015. 6(5): p. 363-372.
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- 8) Leung, K.Y., Recent advances in preimplantation genetic diagnosis. *Hong Kong Med J*, 2015. 21(4): p. 296-7.
- 9) Ishii, T., The ethics of creating genetically modified children using genome editing. *Curr Opin Endocrinol Diabetes Obes*, 2017. 24(6): p. 418-423.
- 10) Kang, X., et al., Introducing precise genetic modifications into human 3PN embryos by CRISPR/Cas-mediated genome editing. *J Assist Reprod Genet*, 2016. 33(5): p. 581-588.



Reflections on Elderly Restraints

Colin Chung Y/2

When one thinks of restraints, one often thinks of the excessively draconian punishments associated with espionage. Rarely does one think of the peculiar incidents happening in many elderly homes; in the desolate corner of poorly-kept housing estates, beyond the creaky door and the browning window panes, quietly rotting away in the humid weather. A slow stream of people: Family members, staff, the elderly, the last often pushed away, making room for another. Most of us pass by, paying no attention to the elderly who are bound tightly to their beds. I had once read that in the average person's life, one is most happy in their middle-aged years, before happiness slowly droops down a slope, before being cut off, abruptly. Would it better for them (and for us in the future when we're old) to be more forgiving, more sympathetic to the elderly?

Does time pass quicker for an older person? Behind the philosophically ambiguous concept that is aging, we come to the (equivocal) end: death. From my current (atheistic) knowledge, it consists of nothing, a cessation of sensory input. From further research, there are numerous definitions of death, one of which would be irreversible cessation of all functions of the entire brain. Akin to the sensation one feels in a sensory deprivation chamber, or one of the elderly, lying motionless on their bed, constrained, incarcerated. Maybe an additional tube or two. Entirely unable to move, to express themselves, to experience the world around them. Is it ethical to deny them their free will (the purpose of which is to prevent death) just to grant them a "living" death? Why doesn't quality of life supersede the imminent danger of dying?

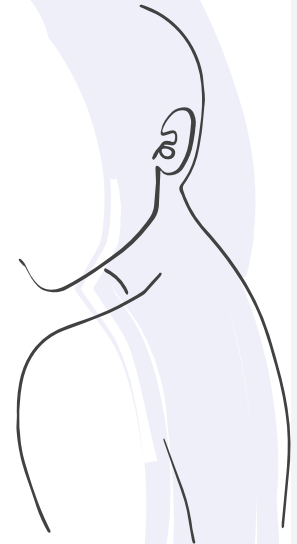
It seems gratuitous to sustain a person's life if that person lives devoid of sensory input. Of course, one might argue that one is still able to hear, and yet this form of eavesdropping accentuates loneliness; They have no participation in any external events. Physical restraints on elderly patients share eerily similar characteristics to a sensory deprivation experience.

It may seem (and it is) logical to sustain life when one considers all aspects of society, family members, human rights and resources available based on our values (demonstrated by the current ban on euthanasia in Hong Kong). But for the person suffering, where emotions trump logic, it would seem like a contrived attempt to torture them for the convenience of others. It is impossible, impractical even, to be emphatic of a person's predicament. However, if we remove ourselves from our conceited mindsets, one may comprehend the pain, the emotional turmoil, the estrangement from society one faces.

In our lives, we are exposed to a myriad of unfortunate events; These desensitize us to the sufferings of others. We are blindfolded by our ego, constricted by our laziness, incarcerated by our rules and regulations, unable to understand their querulous struggles against the tight leather straps, their furtive motions to remove their life-sustaining devices. Is that not symbolic of life itself? The upward climb to better conditions and comfort (to utilitarians and perhaps zealots) or fulfilling religious doctrines, or the futile chase for meaning (for philosophers and nihilists), and everyone in between. Utilizing our struggles enables us to be more empathetic, and then, we will be more compassionate, more forgiving to the wide-faced, stout grandmother sitting by the windowsill, unable to see the sun and the children playing outside.

Conceptualising Identity: Anorexia Nervosa

Tiffany Yu Y/3



Anorexia nervosa (AN) is diagnosed by the restriction of energy intake relative to physiological requirements, leading to significantly low body weight relative to the minimum expected for one's age, sex, developmental trajectory and physical health. Often, one experiences intense fear towards gaining weight and becomes persistently unable to recognise their severely low body weight. Treatment against the will of patients with AN is considered when patients are at imminent risk of death or permanent damage to their wellbeing.

The need for treatment choices comes with the imperative to respect patient autonomy. This follows the Mental Health Act 1983 in the UK [1], whereby psychiatric inpatients in emergency situations are allowed to be treated paternalistically as it is assumed that physicians act in their patients' best interests. However, the judgment of mental capacity – a component of autonomy – often complicates for persons with AN; it becomes challenging to gauge the extent to which such persons are adequately competent to make autonomous choices in their best interests. We are presented with challenges towards achieving the imperative of respecting autonomous decision-making by patients with AN.

“Respect for autonomy” and what lies in the “best interests” of each patient are tied to their values and therefore appear subjective.

A patient's refusal for treatment may be ignored as their values and identity – entangled in the pathology of AN – differs from that of their physician. AN can be conceptualised and perceived as intrinsic to the identity of persons with AN. In this light, how AN influences patients' self-perception, values and priorities might compromise our ability to know if treatment is truly “autonomous”.

On the one hand, if a patient's choices are adhered to but are a result of the pathology of AN and not the patient's genuine will, this may lead to maleficent or non-beneficent actions. For example, if doctors comply to a patient's refusal for treatment regimens aimed to help them regain a healthier weight, their choice would only be respected at the expense of severely compromised health. Thus, to fulfill what the physician deems as the patient's best interest (e.g. increased weight), healthcare workers could exclude patients with AN from decision-making to ensure a smoother treatment.

1) Hudson H. Coercion in psychiatry: is it right to involuntarily treat inpatients with capacity? *Journal of Medical Ethics* 2019;45:742-745.

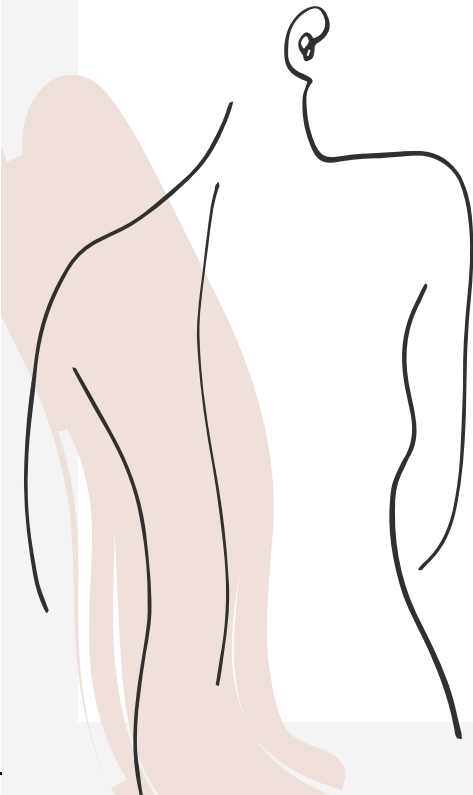
On the other hand, this could preclude the patient from being understood as a competent contributor to important decisions; families and friends may take over the responsibility of consent and the patient's autonomous and "genuine" pleas over their wellbeing could be neglected. Moreover, as the pathology of AN often involves the "need for control", depriving patients of power to decide would impinge autonomy and cause distress.

The great deal of uncertainty about what to do for patients will always remain; lives and disease are complicated for our realities to be otherwise! Hence, doctors have often chosen to agree in advance on what to do amid uncertainty – algorithms for emergencies are created and actions are ordered ahead of time. Yet, decisions made in advance seem to oppose what we believe practicing medicine is all about – to consider and treat each patient as individuals in contexts

unique to them. Ethical healthcare warrants dealing with tensions between eliminating uncertainty through uniformity and respecting individuality with non-maleficence. In the case of patients with AN, making decisions after (rather than before) knowing the patient's context and identity become important, despite how it could complicate the decision-making process.

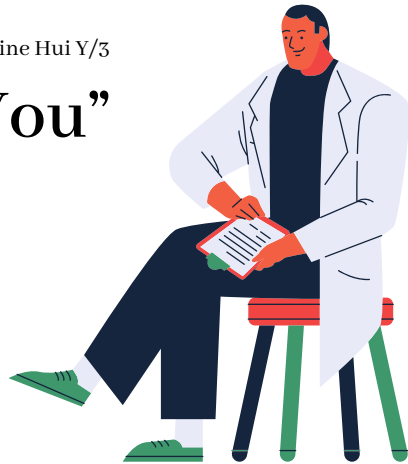
Beyond AN, values and autonomies of patients cannot be fully understood without considering their diagnoses. Better insight into the values, identity and autonomy of patients with AN, and how they interplay with pathological factors of AN may reduce unethical decisions made against patients. Consequently, coercion and negligence in patient care could be lessened. Moreover, through greater acknowledgment, healthcare professionals may be able to develop more trusting and intimate relationships with their patients in a way that involves less perceived coercion, as well as greater perceived autonomy and beneficence.

Comprehensive, case-by-case considerations into how we deal with tensions arising from certainty, uncertainty, uniformity and individualism are key to better understanding gradations that exist in disease, the human condition and choice.



“Dr. Alexa is Ready to See You”

Jasmine Hui Y/3



“Alexa, what are the symptoms of chickenpox?” The government in England has recently announced a partnership between Google’s voice-assisted device, Alexa, and the National Health Service (NHS) [1]. Prior to the partnership, Alexa would dodge most health-related issues with replies similar to: “Sorry, I’m not sure about that.” The tactic of avoiding health-related questions, frees Google from being held responsible for providing inappropriate or inaccurate health information which may alter its users’ decision-making and health behaviours. The rationale behind partnering with the NHS is to allow greater and easier access to accurate healthcare advice. However, there has been controversy over the ethical concerns in the use of A.I in the creation of “Dr. Alexa”.

At first glance, Alexa seems to be an invaluable assistant for users in gaining information — it is essentially an audiobook for the NHS. Indeed, not all questions warrant a trip to the doctor’s office. In an era of mass information, this device will narrow down search results and offer clinically valid information. If used correctly, Alexa will promote proper health-related decision making — advising users to visit the clinic when truly necessary, reinforcing efficient resource allocation. Thus, the concerns regarding Alexa leading to poor health behaviour changes such as, “being one’s own doctor” does not appear to be a strong argument against its implementation as access to prescription drugs or a true diagnosis would still require a physician. It seems benign for users to become educated on their own symptoms and possible diagnoses when visiting their doctor.

However, trust is an important characteristic at play in good doctor-patient relationships, a value which Alexa and the NHS may try to emulate. When answering a health-related question, Alexa will likely offer one answer — creating a sense of legitimacy and authority. In reality, the answers physicians often give in patient consultations are rarely “one size fits all” or straight-forward. Consequently, the questions Alexa will only (and should only) be able to answer are general, non-specific questions such as “What are the symptoms of chickenpox?” rather than “Do I have chickenpox?” or “I think I have chickenpox, what should I do?”. When there is too much trust for Alexa, users may forego visits to the clinic for basic check-ups with human physicians. As such, Alexa must take caution in reinforcing that one’s local GP should be the most important.

Trust can be undermined in the trade-off between privacy and convenience. There may be privacy issues concerning whether medical information is recorded by Alexa and stored on the Cloud. Claims that such information is encrypted or erased may not be definite. Moreover, is there a way to hold Google or the NHS accountable if inappropriate changes to health actions are taken?

Alexa may evade such problems of liability if it is not considered a “medical device” as it would still be able to function as a personal assistant. Data privacy should be highly regarded and carefully managed. Indeed, many technologies have the potential to be hacked, but, such sensitive medical information is particularly valuable for profit-driven companies in the insurance and pharmaceutical industry.

Will Alexa be able to sense emotions such as anxiety in users? Should we be entrusting this voice-assisted algorithm in answering questions that may have otherwise lead to a graver diagnosis such as cancer? Will it have an alarm system that flags individuals or contacts health professions in emergency situations?



Are we willing to form a relationship with robots, knowing that their words lack the intention and connection humans have?

For example, the actions that have to be engineered if a user were to claim to have suicidal thoughts would be complex. In addition, if Alexa did not automatically contact help (e.g. in fear of inappropriately disrupting emergency services), there would not be a guarantee that users will pursue help even if suggested. The delivery of sensitive advice and counselling by Alexa would need to be carefully designed and different to the currently witty interface. Another interesting question is whether machines can truly emulate human attributes like empathy. Are we willing to form a relationship with robots, knowing that their words lack the intention and connection humans have?

It is evident that Alexa has dual purposes — is its purpose to truly help consumers or to train their own algorithm to become smarter? It is one thing to ask for the help of individuals in data provision but it is another to create a reciprocity system that has the potential to harm. Enhancing access to health information for users promote patient autonomy in decision making. However, ethical considerations for privacy and increasing transparency on how the technology behind Alexa works must be addressed before introducing new devices onto the market.

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A Vexing Issue

Emily Wai Yin Leung Y/5

A boy was caught crying, and jaw clenched, while his arms were twitching, followed by severe body rigidity and exaggerated arching of the neck and back, so much so that it looked akin to the Sydney Harbour Bridge - but, *he wasn't throwing a temper tantrum, he simply couldn't help it*. Then shortly after, his breathing began to fail and he was urgently air-transported to the closest emergency room - it was truly a close call had he not been monitored by his parents. It was unfathomable, to his family and friends, that a seemingly healthy, sweet boy playing on a farm six days ago and sustained what everyone thought was at worst a forehead laceration could devolve into this now-barely recognizable human being. The agony and pain had left this mere six year old boy defeated, mentally and physically - and certainly, no less his parents, who must have been sickly worried and caring for him by his bedside this entire time. *But what if I tell you his parents were the ones to have put him in this situation in the first place?*

This boy suffered from what is known as a horrifying disease called Tetanus caused by *Clostridium Tetani*. A disease that can leave his body involuntarily spasming for weeks, sometimes the force is so immense that bones are fractured and tendons pulled from their origins. Without timely intervention, his diaphragm, like the rest of the body's muscles would fail to relax and suffocate him to death. A disease that should have been eradicated for decades thanks to the advent of DTaP vaccine which is given in a series of 5 doses at different ages, has made a comeback here.

In the United States, reported tetanus cases have declined more than 95% and deaths more than 99% since 1947 [1]. This extremely unfortunate and also disconcerting case of pediatric tetanus was the first to be recorded in the state of Oregon in over 30 years and was reported on CDC [2], all while this boy could have been saved if only his parents didn't opt him out of his "required" DTaP vaccines.

Now, imagine instead of a disease as such that is contracted via direct contact with the bacterium but an infectious disease that can be spread airborne which many children were not vaccinated against. The stakes become even higher. This is exactly why we have seen a dramatic climb of 300% in reported measles cases just in the first three months of 2019 compared to 2018 globally [3]. Ironically, it was a first-world country such as the US that had declared a state of emergency in a couple measles-stricken areas as part of what is known as a 2019 Pacific Northwest Measles Outbreak [4]. All thanks to a growing movement led by so-called anti-vaxxers who publicly advocate for no-vaccinations and spread misinformation about vaccines.

Autonomy and Maleficence

First, the principle of autonomy dictates that an individual should have the choice to make his/her own decision. Like in Obama's healthcare reform the clause of individual mandate that requires everyone to buy health insurance has caused a major uproar in 2010, it is equally a dilemma to mandate vaccination in a country like the US where freedom is of utmost value. This explains why the all 50 states grant exemptions to children for medical reason, while 45 states and Washington DC grant religious exemptions, and 15 states allow philosophical exemptions (simply put, whatever excuse floats an anti-vaxxer's boat is a sure-win anyway).



Painting of opisthotonus in a patient suffering from tetanus by surgeon and artist Sir Charles Bell in 1809

Question is, however, what is the price of freedom? The efficacy of vaccination relies on a concept called "herd immunity" wherein a significant portion (or a threshold) of population have to first be vaccinated in order to provide a measure of protection for individuals who have not developed immunity to a disease. Often times, this group includes infants, children, immunocompromised individuals and the elderly. With enough anti-vaxxers or people with other exemptions to defy the benefits of vaccination, vulnerable groups are harmed (given globalisation can easily diffuse it to other countries already prone to all sorts of bacterial and viral diseases or do not have equitable access to vaccines), directly leading us to the principle of maleficence.

What has not been revealed regarding that poor boy's story, also, in relation to this principle is he actually ended up requiring 57 days of inpatient acute care including 47 days in the intensive care unit. All while these hospital stays meant he had to be intubated, restrained, closely examined, and simply hoping to be able to breathe on own again if not for the basic survival instinct of also eating normally again. If in the case of measles, patients who are lucky enough to have been diagnosed early for medical intervention and sent to hospitals would require complete isolation with few family visits allowed.



A group of demonstrators in Washington protesting the voting on a law that would tighten loopholes for not vaccinating in response to the measles outbreak in early 2019.. Credit: Ted S.

Warren (AP)

Besides the physical damage, the psychological suffering is surely insurmountable. For this boy, his inpatient charges had racked up a cost of USD\$811,929 (excluding air transportation, inpatient rehabilitation, and ambulatory follow-up costs), which is equivalent to about 6.3 million HKD (mind you, this is enough to buy a decent one-bedroom flat in Mong Kok, which is sadly an unattainable dream for many youngsters these days) [2].

And the financial burden brought forth to the family, the hospital, insurance company, government is unduly and also unnecessary in the first place. However, before discharge, the mother of this boy still declined the second dose of DTaP and any other recommended immunizations. One case is simply already too many.

Justice

Is it fair to then risk vulnerable individuals in homeland and abroad, because of some unjustified and false claims (e.g. vaccine causes autism) held by anti-vaxxers? This appears to be a violation of the principle of justice. In addition, shouldn't social media platforms be held accountable as the primary vessel for the spread of such misinformation (it is essentially "false news")? In the past decade, epidemiologists have linked decreased immunization rates to the increasing prevalence of social media [5]. One could argue that the principle of justice is not hereby violated, because when a majority group wholly invalidates a minority group's opinion and limits their freedom to speak up, injustice was constituted in the form of discrimination in the first place. To these anti-vaxxers, their fear of autism is real. Just look at this article published in the New York Times [6], amid a measles outbreak the State of New York has actually ended religious exemptions for vaccines as a public health measure in June 2019 so all school kids have to be vaccinated. And the anti-vaxxers parents' response?

They are taking kids out of school! This is how far they're willing to go to avoid vaccinating their children. Hong Kong may not get to enjoy the chanting and behavior as such from anti-vaxxers. And Hong Kong's vaccination rates have remained at a global high of at least 95% as of April 2019 [7]. It would still not be surprising if there is a silent group of "anti- vaxxers" amongst us and most likely in mainland China. It is reasonable to deduce so given the repeated scandals of fake or expired vaccines manufactured in mainland and as a result, the plethora of fear and distrust, which also sparked a wave of mainland customers visiting Hong Kong private clinics and hospitals for these needed vaccines.

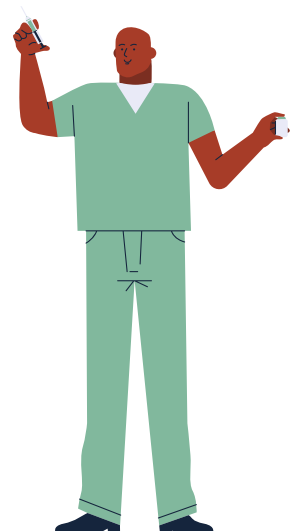
Beneficence

In light of all this, we're ultimately led to the principle of "beneficence". Beneficence is unequivocally earned when herd immunity is in place and less susceptible individuals are at risk. We may thereby argue that protecting this principle entails killing any misinformation and the unfounded movement it perpetuates, before the wrongs hands would in turn "murder" more human beings. It is therefore paramount that government health officials and credible figures in society come out and debunk this hoax about the link between measles vaccine and autism, wisely through public education and propaganda.

This issue of vaccination is likely an emotionally vexing one for many - those who have suffered at the hands of misinformation, those who have advocated for and those against - it's evolved into a chasm. It is an issue that has rolled back years of sensible public health work and warrants attention at the front of bioethics. This article was meant to be a distilled piece of a multi-layered, complex issue, and at its core lies the value of human lives.

The six year-old boy, like all other children, deserves a life free of preventable pain, to play safely inside the house or outside in a crowd, in the mud or on a playground, without fear of being attacked unnecessarily.

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Lessons in Dissecting Life

Justin Chow Y/3



After brief instructions, we unzipped the cadaver bag and unveiled our 'silent teacher' for the first time. There, a body lay before us – in its most natural and organic form. It was the moment to make the first cut, the perceived 'rite of passage' of a medical student entering their rigorous professional training.

At CUHK, human body dissection constitutes an integral part of anatomy learning, with the support of the University's 'silent teachers' body donation programme. Prior to each dissection class, students are provided a list of body structures to study. During the class, we dissect the cadavers and look for anatomical structures, and then present our findings to our professors.

For the first few months, I was not particularly confident in doing dissections, sometimes for the fear of making mistakes and sometimes for the doubt over my knowledge on anatomy. It was not until the second semester that I gradually gained stamina and increased my involvement in hands-on work. Getting accustomed to dissection skills was certainly one reason, but more importantly it was a change of my attitude: I learnt that the dissection sessions were not merely about locating the structures (which I worried I could not), but it was also about *exploring the body*.

With a newfound understanding of dissection, I was surprised to read the other day that, many Western medical schools are moving away from 'conventional' dissection learning. Reasons cited range from limitations of cost and teaching time, to mental preparedness of medical students. In place of cadavers, a combination of prosected specimen demonstration and 3D technology (such as visualisation softwares and dissection simulations) has been increasingly favoured in practical sessions.

In fact, many aspects once unique to dissection are no longer so. The opportunity to work in "3D" used to be the privilege of dissecting cadavers. Nowadays, simulation kits have been developed to demonstrate cross sections in various planes, and to show relationships between structures, layer by layer, organ by organ. In some institutions, dissection is now employed primarily as a 'taster' for students to handle surgical instruments. In other words, the significance of dissection has become less of a means of anatomy learning per se, but that of a bridge to clinical training.

Indeed, in many ways, dissection can be considered as providing a foundation for students' future surgical training, most notably the experience of engaging hands-on work. Nevertheless, the two have marked differences: cadavers possess a different texture from living bodies (due to the preservation process), and very importantly, there are no 'medical' consequences in the event of mistakes. Dissection, though serving as a basis for, cannot be taken supplementary to surgical learning. So what makes dissection still worthwhile, at least from a clinical point of view?

I believe the difference rests in the practice and study of medicine. In surgical training, one aims to *carry out* an operation – a specific structure is targeted and located with reference to clinical knowledge. In dissection, however, one aims to *investigate* the human body – a region is exposed such that we may *explore* and realise the relationships of neighbouring structures. Learning anatomy through dissection is the process of discovering, trying, tracing, and learning from mistakes; finding the right structure is the culmination of all previous efforts. The capacity to fulfill all these elements in learning, with little doubt, is best offered by cadavers. This was, to me, a major takeaway from last year's practical classes.

Aside from the clinical viewpoint, also frequently discussed is the role of dissection in fostering students' bioethical awareness, as a result of learning from 'silent teachers'. Currently, the academic field remains divided on this issue. Institutions which do not offer anatomical dissection emphasise the incorporation of bioethics in their medical curricula, ensuring that relevant bioethics principles are thoroughly addressed in class. Nonetheless, I fully echo the idea that, the experience of dealing with 'silent teachers' in pre-clinical training helps provide students with early exposure to topics like life and death, and instills a sense of admiration for the deceased.

In the process of dissection, I have come to appreciate the uniqueness of each 'silent teacher'. On the physical level, that is to say, the anatomical variations. True, we can simply refer to textbooks or literature to learn about different variations, but obviously we can never make presumptions of the variant possessed by each 'silent teacher'. In dissection, we must work to figure out which one variant he or she has. Perhaps, this is what learning through dissection means to us: work to discover for ourselves.



"Silent Teacher" Body Donation Program at CUHK
Credit: Green Burial Gov HK

Each 'silent teacher', at some point in time, used to be a living soul with thoughts and values. To work on a 'silent teacher' is not only the means to consolidate anatomy knowledge, but also the opportunity to communicate the will of good deed that they have left us with. If I were to extrapolate human anatomy on the spiritual level, I would say: just as every person has the same set of organs in the body, every person undergoes the same process of aging and death. Yet, just as how the structure presents itself in the body is variable, how one interprets their life is different. We must be patient in order to know a person well, just as we must be patient and respectful when exploring each cadaver's human story.

On a sunny day, we scattered the ashes of our silent teachers at the Garden of Remembrance. Many of our 'silent teachers' were not medical professionals themselves, nor did they have a taste of dissection in their lifetime. But they have chosen to leave us with an immensely important asset – their body. I always remind myself not to take dissection sessions as granted; they are an additional blessing placed upon us medical students so that we can experience the love of mankind before we go and serve others.

Diseases Without Borders

Thiashya Jayasekera Y/3



Outbreak after outbreak, from Ebola to Zika to Swine Flu, the media highlights groundbreaking biomedical innovations as the solutions to our global health concerns. Mosquitoes for mosquito-borne disease, genetic modification, development of antimicrobial vaccines – these are the marquee solutions when it comes to combating modern-day disease. However, are these really the solutions that we need? Or do we already have the means to solve these issues at hand?

Prior to the advent of modern medicine, major Western cities tackled illnesses through preventative strategies. There is no other alternative as there was no biological cures before the understanding of the biological basis of diseases. In 19th century London, cholera and tuberculosis were rampant and there was no treatment available, much like our current predicament with infectious diseases such as Zika, Ebola and HIV/AIDS.

The 1854 Soho outbreak of cholera was devastating, killing 500 people in just 10 days. Whilst no biological cause for cholera was known, physician John Snow came to the conclusion that it originated and spread through a shared water pump, after he meticulously mapped each case and monitored the progress of the outbreak. The discovery was met with skepticism, yet enough to lead government officials at the time to invest in sewage and sanitation systems, thereby protecting a rapidly growing urban population. This snippet of history illuminates how urbanisation and population growth can lead to the spread of disease, and the importance of political intervention and non-biological prevention in combating such diseases. Snow also demonstrated the significance of epidemiological studies in combating disease, making it one of his many contributions to the field of public health.

The importance of data surveillance has been made evident more recently in the West African Ebola outbreak. The areas which suffered most were those which lacked infrastructure and surveillance systems. As a result, the World Health Organisation (WHO) was slow to recognise and declare Ebola a public health emergency, and found it difficult to direct resources to where they were most needed afterwards. This tragedy highlights again the importance of data surveillance and additionally reflects the inability of international organisations such as the WHO to adequately respond to and manage global emergencies.

As stated in its report 'Combating Emerging Infectious Diseases', the WHO recognises the "importance of strengthening global surveillance mechanisms". However, the Chairman of the Review on Antimicrobial Resistance, Jim O'Neill, notes, the lack of a universal surveillance system, especially in developing nations "deprives us of the key insights and early warnings that we need to mount an effective response". Whilst biomedical fixes are important, they are band-aid solutions. The causative agents of these diseases can be identified and we can statistically monitor their prevalence of mortality rates, disability-adjusted life years and incidence rates. Apart from these biological causative agents – parasites, infections or whatever it may be – there are important (perhaps even more important) non-biological agents at play. Shockingly high prevalences of preventable diseases in the developing world is proof enough that biomedical solutions are not effective stand alone.

Take diarrhoea as an example. According to the WHO, diarrhoea is the second leading cause of death in children under five globally and kills more children than AIDS, malaria and measles combined. As UNICEF Executive Director Ann M. Veneman stated, “it is a tragedy that diarrhoea, which is little more than an inconvenience in the developed world, kills an estimated 1.5 million children each year”. What is more shocking is that standard diarrhoea treatment – oral rehydration therapy – is simple, inexpensive and life-saving. But despite this, only 39 per cent of children in need of this treatment receive it and there has been little progress since 2000.

However, perhaps rather than treating the symptoms of such diseases, more focus should be placed on tackling the causes. The causes of diarrhoeal deaths can be superficially laid down to the biological causative agents – to rotavirus, shigella virus or E. Coli bacterium. But ultimately, the causes of these deaths stem far beyond the biological agents, down to issues of poverty and inequity, manifested in the forms of malnutrition, lack of sanitation and poor access to healthcare.

A 2009 WHO/UNICEF report “Diarrhoea: Why Children Are Still Dying And What Can Be Done” outlines seven recommendations for combating diarrhoea – five of which are preventative. These measures include: providing access to potable water, improved sanitation, hand-washing with soap, exclusive breastfeeding for the first six months of life, good personal and food hygiene, health education and rotavirus vaccinations.

The same report suggests that such disheartening statistics are partly due to other preceding global health emergencies.

As UNICEF Chief of Water, Sanitation and Hygiene, Clarissa Brocklehurst stated, “Other diseases have come in and caught the spotlight. What [this] means is that spending on the ways to reduce diarrhoeal diseases is completely disproportionate to its impact”.

This brings about the question of how we should equitably allocate resources and funding. Should we operate within a purely economic framework and monetise lives? Should we invest our money in what brings us the greatest marginal return in terms of lives saved and quality of lives improved, or should we allocate our resources to the areas of greatest need? And if so, how and where we should direct our attention, resources and money?

It needs to be understood that diseases manifest from social conditions – poverty and inequity – as well, so our solutions must address both the biological and non-biological causes. Any biomedical solutions to global health issues must operate alongside socio-political interventions. And by tackling disease through addressing issues of infrastructure, data, sanitation and equity – we can systematically combat a whole host of diseases with better ease, and without having to direct all our effort to any specific one.

Of course, it is much easier said than done, and such changes are slow and difficult to enact. But when it comes to our global health, by no means is there a quick-fix.

Justifying Human Infection Studies

Yannie Wong Y/2

The advancement of medical research in the last few centuries has eliminated many diseases that were once deadly. Smallpox, for instance, was once a highly dangerous and contagious disease. It no longer poses a serious threat to society as it has since been eradicated through the World Health Organization's global vaccination program [1]. Clinical trials play an essential role in the acceleration of medical development, thus human infection studies are still invaluable in current medical research. To better unravel the pathogenesis of Malaria, the Kenya Medical Research Institute actively recruited volunteers to participate in an infection study with a remuneration of Sh 48,000 [2]. The primary data collected from these human infection studies are likely to greatly contribute towards the invention of new vaccines. Nevertheless, there is a plethora of ethical concerns and complications revolving around this practice. This essay aims to investigate the dilemmas and moral issues surrounding human infection studies, and to discuss whether such a practice can be justified.

The core dilemma of human infection studies concerns whether scientists should "infect healthy individuals with a potentially harmful organism" [2]. As each different creature is comprised of a different genetic makeup, directly infecting human beings can generate results which cannot be easily obtained from experimenting on other species. Through human infection studies, scientists are able to gain a more comprehensive insight into how the disease infection cycle affects mankind, and identify specific DNA sequences that make certain humans more susceptible to infection or more severe symptoms. Not only will the primary data collected benefit research in epidemiology across the globe, it will also speed up the development of medicine by increasing the effectiveness and specificity of the cure. The discovery of more potent drugs could potentially prevent outbreaks and pandemics, which would

have otherwise affected millions of innocent lives. Volunteers recruited for the program were well-informed about the risks of the study and gave consent. In addition, specific guidelines were implemented to safeguard the volunteers' interests, thus human infection studies may seem like a flawless model for more advanced medical research [3]. However, there are some concerns regarding complicated moral implications befalling such studies. One of the major arguments is that the monetary compensation offered may impair the volunteer's capabilities to make rational and autonomous medical decisions. One might then doubt the validity of such consent given to participate in human infection studies. This is especially true in those trials organized in areas with relatively low socioeconomic status, since the volunteer's primary interests would likely lie in the financial returns rather than a genuine will to participate in such research. Although the money was given as a form of compensation for the volunteer's contribution (e.g. blood sample and data) in the studies as opposed to a payment to purchase consent, it is still possible that such a practice could impact an individual's decision-making capability, and to a certain extent, distort relationships between scientists and local communities.



Credit: Steve Ringman (ZumaPress)

Largent addressed this issue by stating that monetary incentive used in research might be considered immoral. This is because even though “the payment might not distort a prospective research participant’s ability to weigh the risks and benefits of participation”, many people still maintain an “idealized view that research participation should be motivated by altruism” [4]. Given the compensation in the studies was based on the “minimum wage for casual laborers in Kenya”, the amount offered is unlikely to be significant enough to impair an individual’s capability of making free medical decisions. Therefore, although the practice of financial incentives might not be aligned with the virtue of altruism in scientific investigation, and may increase an individual’s interest to participate in the studies, it is unlikely to affect the validity of the consent.

Some might also question whether human infection studies violate the categorical imperative of non-maleficence. Whilst the argument might seem compelling as the categorical imperative is independent of circumstances, human infectious studies are unlikely to cause harm to volunteers for at least two reasons. First, there are strict protocols to minimize pain, and to safeguard the interests of volunteers. For instance, the “Bill and Melinda Gates Foundation issued guidelines aimed at protecting participants” [3]. By carefully observing these rules, experimental conditions are highly controlled to prevent unbearable harm done to participants. Second, volunteers are immediately treated if any symptoms emerge. They would also receive additional compensation for their contribution [2]. Therefore, the argument based on non-maleficence is invalid as any harm to the volunteers is reversible and short-term. In addition, the volunteers are aware of such risks from prior briefings. Kant’s categorical imperative of non-maleficence, hence, cannot be applied in the context of human infection studies, as the research itself does not constitute as “harm” towards the volunteers.

In conclusion, while acceleration in scientific and technological development improves the health conditions of communities, it is equally important for mankind to examine the ethical implications behind the methodology. Specifically in human infection studies, justification might not be apparent at times due to the complicated nature of such experiments. However, informed consent, which embodies the element of respect between the volunteers and researchers, and a genuine goal to alleviate human suffering, should always remain the core values in every research study. Philosophical frameworks might not necessarily lead us to the ultimate answer, but they can at least act as a beacon, guiding us whenever we are bewildered with conflicting opinions. It is always important for us to appreciate the complexity of science as an art, and embrace diversity as an integral part of human civilization. At the end of the day, though a unanimous consensus might not be reached, it is nevertheless ideal to acquire the capacity to accommodate diverse ideas and opinions that give momentum for society to progress rapidly.

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