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## Editorial: Extending Humanity

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Are you happy the way that you are? How could you be improved? One of the visions of the 21<sup>st</sup> century is that this will be a century extending the meaning of what it is to be human. We can reflect on the meaning of humanity in many ways. Let us start by asking what it means to you to be human? Is it defined by your DNA? Can a computer become human? Can a chimpanzee become human?

Is humanhood defined by holding some paper which describes you as a citizen of one country? There are many stateless people in the world who are denied identity documents, and with the growing number of refugees in the world unless we have universal citizenship the number will increase. Not only are there cases that a person cannot get a document to call them a human citizen of a country, it is still official language in the United States of America to call non-citizens, aliens. Non-citizens have an alien registration number, and aliens are divided into legal aliens and illegal aliens. This was also a term borrowed by Japan in the 1990s, which then dropped this term.

Is it defined by wearing clothes? The clothes market for cats and dogs is rapidly expanding, with many clothes available for cats (See Figure 1).



Figure 1: Pet clothes shop in Japan

So many animals have been treated as persons even before the clothing craze. There can be some bioethical arguments to support clothing, for example extreme cold, or booties to avoid getting cut feet from broken glass on

beaches. Horse shoes have been used for centuries, and breeding rams have been fitted with false teeth so they do not starve when their teeth wear out.

Is humanhood defined by attending school? Pet schools are places for pets to learn many skills, and the language of instruction is usually that of the local human language. If we defined by our parents, being raised by human parents, than that is something true of pets as well. The idea of social order, and discipline is associated with what it means to be "civilized", and in a planet with a burgeoning population discipline is essential. Too much law and order has been an antithesis to a vision of situation ethics where love determines what we do, and our moral limits.

The ideas of transhumanism usually refers to going beyond current human capabilities to create a human being that is enhanced in some way (Boyd, 2018). There have been many papers that discuss the ethical, legal and social implications of genetic enhancement, and in research I have conducted since 1991 we can find widespread support for genetic enhancement, especially in developing countries in Asia (Macer, 1994).

The concept of enhancement is not something that is only targeted through genetics and diet - educational and social systems have been engineering persons over millenia. All attempts at education to transform our mind as we grow up, are efforts at enhancement that most societies support.

Racism, sexism and harmful discrimination remain principal ethical challenges for the development of society. Despite efforts to reduce sexism, in the past several years we have seen the reemergence of racist talk and thinking in countries such as the USA. The voices of political leaders and some extreme media are acting counter to the ethical evolution of human society to be one free of discrimination.

We certainly need more moral beings, and religions have not always helped this. John Bowker (2018) wrote: "Religion Hurts: Do religions cause more harm than good?" The message of love and moral accountability are essential in the spirituality of morals. Boyd explores the arguments for and against transhumanism, taking a holistic perspective. Only time will tell if our future human experiment with genetic engineering will be any more successful than efforts through religion and international human rights law have been, in making us any more "human?" than mere selfish "tribal" warriors. This use of tribal is not written as a derogatory term for indigenous persons, who have coexisted across the world despite attempts to globalize us all into one human order. In spaces that have resisted colonisation that was usually enforced by military might, we can still find thousands of population groups. The progress of enlightenment as an experiment is mixed in its outcomes, with many atrocities having been committed in the name of social progress.

The emergence of human rights law and greater knowledge of each other are successes. However the existence of rapid communication across the globe, does not mean that we will always be peaceful. There were celebrations of the first trans-Atlantic telegraph cable, with claims that this would be the end of war. Soon however, we realised that it also matters what we say,

and how we say it. We need a peaceful and loving communication with listening between people.

The second paper in this issue refers to one example of technological transhumanism - keeping dead or vegetative maternal bodies alive as fetal incubators (Kouy, 2018). Although this practice can be consistent with the interests of a mother or family to propagate the next generation, it also is so easy to be viewed as a commodification of a living body for the needs of another. If we extrapolate this idea even further we can question the meaning of society where people labour for others, some die in battle to protect nations, some work like slaves to make cheap consumer goods, coal miners die to produce electricity, and so on. Most people do not choose to work with these risks, but the economic system forces them to do this.

Bioethics as love of life is a vision that all life will love to live, and love other's life. I still believe in this utopian dream as the image of what human beings should and can become. Making choices starts as children, as discussed in the paper by Sumaira Khowaja-Punjwani in this issue of *EJAI*B. We need to recognise the ontological evolution of assent to consent, and to reasoned choices, in developing our humanity. Until recent times no children had freedom of choice, and we are starting to see this emerge.

Herlambang et al. review some of the cybersecurity challenges in a Hospital Management Information System. The protection of personal data against human error through a well developed information system should also be balanced with the security concerns to protect data. Amrit Dhimal provides some of the issues faced in the tourism and hospitality industry, which is one of the ways that humankind are brought together.

Lastly there are two papers on public health issues from Ann Boyd and colleagues, firstly on the ethical challenges of the Zika epidemic, and the second more generally on global public health. Although we may pursue the development of transhuman beings we would do a much more ethical and better job of making the most out of our fragile lives if we lived healthily in harmony with nature and all of life.

Thus from the discussion of reductionism in the first articles, we move to consider a more holistic approach to life and health. It mirrors a transition in consideration of the central dogma of molecular biology that we saw in the 1980s, with DNA→RNA→Protein, that has now moved to DNA←→RNA←→Protein. While we have physically engineered many organisms to produce food, medicines and other products, we still have failed to deliver many proven enhancement to all human beings on our planet to have a good life. The universal love of others is the greatest extension of humanity that we might ever be able to do. Let us try harder.

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## Transhumanism Challenge to Bioethics

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### Introduction

Transhumanism is a philosophy of life seeking continuation and acceleration of the evolution of intelligent life beyond its current human limitations by means of science and technology. Valuing reason, science, progress and longevity, transhumanism is a form of Enlightenment Humanism reliant on technology. Three areas - genetics, nanotechnology and robotics, receive the most attention as the path to enhancement. The excitement about the potential to change the human blueprint reflects the potential to relieve genetic disorders and improve human quality and quantity of life. Advocates of transhumanism focus on extended enhanced life as an autonomous choice. The reasoning is that the enhanced will have greater abilities that would enable them to create ways to benefit the rest of society. Alternatively, the distinctions between the enhanced and unenhanced would grow until species identity becomes questionable. Will the transhuman no longer recognize ordinary humans as persons or neighbors but a distinct species? Transhumanists claim that technological innovations of the past have strongly improved human life and wellbeing. The agricultural revolution enhanced nutrition and food supply but millions still starve in our world. Today the availability of cell phones and the internet connect people around the world making communication easy and yet wars and conflicts continue. If it were possible to increase sympathy and altruism by making genetic changes to the human genome would it be a universal good? Bioethics emerged in the intersection of unprecedented challenges of medical technology. This paper will explore some ways bioethics could answer the transhumanist challenge.

### Radical enhancement

"*The Principles of Extropy*" was published in 1990 as a transhumanist philosophy in which extropy is defined as "the extent of a living or organizational system's intelligence, function, vitality, capacity and drive for improvement" (More, 2003). Rational thinking includes questioning all precepts of faith or tradition, and experimenting and challenging evolutionary progress. By intervening with technologies that will enhance intellectual acuity, and longevity without the negative aspects associated with aging, human beings will survive and thrive in this putative posthuman world. It is hard to imagine anyone freely resisting all the wonders of longer lives with enhanced intellectual and creative capacities.

Proponents of radical enhancement include representatives from different disciplines, such as Ray Kurzweil (technologist), Aubrey de Grey (psychotherapist), Nick Bostrom (philosopher) and James Hughes (sociologist). Suppose you were offered the chance to boost your intellect to the extent that you

could think like Einstein, compose like Mozart and live 400 years without the negative aspects of aging. Would you want to be an enhancement subject? This sounds wonderful, so who could object? How many peers would you have at 400? How might the way we value life change? The talent spectrum of human capacity is diverse; will transhumanism make it more so, or might technology erase limitations now separating persons? (Bostrom, 2013).

Reaching for radical enhancement through genetics, nanotechnology and robotics (GNR) to overcome current human limitations is the goal of radical enhancement. If capacities far exceed today's "normal human" would it lead to separate species of being? Nicholas Agar suggests that the posthuman will not be of the same species as *Homo sapiens* (Agar, 2010). The human genome sequence is at hand and genes are being matched with location and function. This progress in genetics offers the opportunity to correct mistakes that cause disease and limit life. If mistakes can be corrected, then why not go the additional step to enhance human functioning?

Nanotechnology offers a means of human transformation using microscopic nanobots, introduced into the human body to purge arteries of cholesterol, fix glitches in the memory, carry a drug, or block a dangerous gene's expression. With the development of optical and quantum nanocomputers, amplification of intelligence could expand cognitive capacity of the current normal human. How might enhanced capacities help solve complex problems, and what impact might they have on human identity? The time is now for open debate and deliberative dialogue about all the technologies that fuel the enthusiasm of the transhumanist movement.

### Ethical Responses

Two ethical objections to transhumanism are that it reduces human nature to a biology/genetic system that can be engineered and overly emphasizes human reason. Even if the human condition can be improved through reason, science and technology, it is important to retain the importance of the relational capacity of human persons. The posthuman projects of transhumanism represent ideas about human development in a technological age. They represent the narrow view of human physicality subject to technological improvements, and invite careful thoughtful reflection on the relationship between humans and their environments, artifacts and tools in a digital and technological age. The social improvement hoped for requires equal access to technology, a concern for the wider community which puts autonomy in tension with social justice (Garner, 2011).

Savulescu (2005) makes the point that in order to prevent harm, moral normalcy is not good enough. What is needed is a better cognitive capacity to solve complex ethical issues. "Our own species-specified natures are a rich source of much of the thoroughly unrespectable and unacceptable-susceptibility for disease, murder, rape, genocide, cheating, torture, racism" (Bostrom, 2005). If this is the perspective of human nature, it is easy to see why mere humans need improvement and why technology is the hoped for means to a better humanity.

I wonder if this improvement/enhancement will be aimed at the common good or individual good? Further I question if the gap between knowing what is right and good and acting accordingly will be bridged any better than a person well educated with a well-tuned moral compass. Engaging with others in deliberative dialogue about the values and virtues of overcoming hardship, shaping a life that makes the most of the limits, strengths and weaknesses that define us, is the moral enterprise today. What it will become in a posthuman world is hard to imagine. Unless the posthuman is equipped with more empathy and compassion than the contemporary executives in businesses such as pharmacology, making improvements available to everyone everywhere will be slow if it is a priority at all. In the interim, the gap between the enhanced and the unenhanced may create great obstacles to maintaining communities, or respecting the dignity of all persons.

The God machine metaphor shows us that it may be possible to implant a device in the human brain that would inhibit one from harming another person (Harris, 2014). If universally applied, it would reduce or eliminate violence and wars. Do individuals have a choice? Harris argues that there are times when an ordinarily wrong action would be considered good, that there are times when a person should act to save a life by taking aggressive – even hostile action. For example, in order to save the life of an accident-victim, a limb may need to be amputated. This is a harm, generally speaking, but saving the life is a greater good. Moral philosophy acknowledges that what is good or right is situation sensitive. If hurting an agent about to do harm is not finely controlled, the emergency rescue person might not be able to save the accident victim. Another possibility is that harming the environment by discarding waste products along highways would be inhibited by the mechanism and those who would take economic risks that endanger the savings of many people, could be stopped. Ethically, it should be a concern, who and how the machine that seeks to control behavior is programmed.

### **Bold initiatives for large problems**

Proponents are quick to point out that past enhancements have not triggered speciation but have greatly benefited humanity. The discovery of antibiotics, sterile surgery, anesthetics, mood altering drugs, vaccines, have improved quantity and quality of life for the much of humanity. Yet, it is clear that everyone everywhere does not enjoy the benefits equally. Ninety percent of research and development is done in the “developed world” whereas 85% of the population live in “developing regions”. As the human population approaches 8 billion, water scarcity and climate change are more threatening than infectious diseases.

The patent system illustrates the winner take all approach to distribution of human improvements. Aiming to encourage innovation, intellectual property protection for 20 years give license to companies to charge exorbitant prices for their products. Pharma sales in 2010 were \$307 billion, with 21 new discoveries making it to market out of 10,000 compounds tested. The path to regulatory approval for a new drug is 12 years at a cost of \$100 million - \$1.2 billion (Ness, 2015).

This brief review of how we currently assure equitable distribution of newly discovered drugs that are intended to benefit human beings puts in perspective the claim that “posthuman beings would no longer suffer from disease, aging and inevitable death...by means of technology” (Moe-Lobeda, 2013).

The discovery of embryonic stem cells’ ability to replicate in culture and differentiate into any type of human cell opened the possibility of new therapies for tissue and organ repair. The first reports in 1998 created public policy discussions, creation of new companies to pursue the technology, and bioethical debates. The questions asked were about unintended consequences of unknown risks, juxtaposed with concern about the risks of not pursuing the research on behalf of those who suffer. For twenty years’ scientists have expanded the search for other sources of stem cells and sought ways of generating specialized cells to treat disease. Regarding each person as an end or goal of moral deliberation as well as the focus of medical therapy confers dignity. Millions of persons with neurological diseases such as Parkinson’s could be served through regenerative medicine. The mandate to love one’s neighbor means the inclusion of those who suffer from diseases. Justice should look at the availability and access to regenerative medicine, who benefits, who is at risk, and what it means to have a preferential option for the disadvantaged. Beneficence and justice support an affirmative answer to the question of stem cell therapeutics (Peters et al., 2010). Can the same argument support pursuing enhancement?

If transhuman projects are successfully achieved, will be they excessively expensive? If only a few can take advantage of their benefits expanding the economic and technological divide between regions of the world, we will continue to fuel resentment and embattled competition. Transhumanism may follow the path of stem cell research. Proponents take the stance that employing all our creative abilities for the relief of suffering is a human duty. In the process of creating stem cell therapies, clinics without federal oversight and patients desperate for treatment are vulnerable to technological-hype and laissez-faire capitalism. The progress of stem cell therapy development is promoted in the private sector, but the duty to ensure safe and effective therapies in the U.S. is the duty of the Food and Drug Administration (FDA). The FDA web site offers advice about how to know if a stem cell therapy is approved or being studied under an investigational new Drug Application (IND). They advise potential patients to ask if the FDA has reviewed the treatment, and to request facts or ask question if you do not understand (FDA website). The stem cell evolving story can be a case study of ethical assessment of technologies that promise human improvement.

### **Neuroscience clues**

Neurobiology shows that we humans are relational beings, that we are nature co-operators and that the development of more complex Biosystems succeed only through cooperation (Klein, et al., 2015). Will it make us better neighbors? Globalization brings groups into common space making it possible for us to recognize our interdependence and potential solidarity. Solidarity is a

moral practice fundamental to a social and cultural structure of relationships. Recognition of the other is a condition of moral and political membership, and shows respect for human dignity. Right relationship is a condition of mutuality, interdependence, care and concern for others and their flourishing. Solidarity is essential to counter the temptation for control and the centripetal forces that obscure our interdependence and lead us to think that we can each build the place of our own being. This does not negate the value of privacy or solitude. Solidarity is not a competing principle but a way of shaping sensibility to inform ethical principles such as social justice. Practically speaking, solidarity takes the posture of standing up for, standing up with and standing up as the other. Moral use of solidarity teaches us to see health not as a personal achievement or genetic lottery but one of mutual responsibility. The quality of our collective health depends on an intricate web of cooperation and interdependence (Jennings and Dawson, 2015).

### Enlightenment rationalism

Transhumanist advocates claim a continuity with Enlightenment rationalism and humanism, by promising greater reasoning ability and more autonomy. Like Renaissance Humanism, education and culture were means to improve human nature. Transhumanist Max More sees science-technology as the path to progress holding firm an existential value of human life (More 2003).

Philosophers of antiquity, Plato and Aristotle, used ideals as visionary and regulative of behavior rather than achievable goals. Plato's forms were aspirations that directed the human life toward happiness and goodness. Aristotle recognized that if we achieved the ideals of perfect courage, justice, prudence, and perseverance we would no longer be human. What separates humans from the divine is an ontological gap. Transhumanists want to "have it all" without sacrifice or suffering, utopian happiness unlimited. Is it possible to have it all without cost and retain those values that currently define the good? Or must values shift to accommodate the perfected posthuman?

Proponents and opponents of transhumanism have cited Nietzsche's *Übermensch* (literally translates as overman and herein applied to both genders, as overhuman). "Man is a rope, tied between beast and overman - a rope over an abyss....what is great about man is that he is a bridge and not an end" (Nietzsche, 1954, 14-15). Nietzsche's overhuman is the ideal person, not an eternal version of the human or a radically enhanced form, rather one that has attained mastery of the will. Kaufmann interprets the overhuman as sublimating ones impulses through the development of character (virtue) (Kaufmann, 1950).

To the transhumanist, improvements in IQ would improve thinking, memory, and recall, thereby improving the reasoning ability and enhancing personhood. This reasoning relies almost exclusively on personhood equating with reason "alone" and bypassing the relational capacities, or defining the values these super thinkers would posit (Aydin, 2017).

Without knowing what values the posthuman will have it is difficult to predict what changes would occur

through a specific means to enhancement, such as germ line engineering. To directly edit or engineer genes to avoid diseases is one ambition of human genetic medicine, but the transhumanist agenda suggests going beyond correcting harmful mistakes in the genome. With the availability of CRISPR (clustered irregularly interspaced short palindromic repeats) and Cas9 (a recombinase) the potential exists to modify genetic sequences at will. Liang et al. (2015) reported editing human embryos to correct the beta-globin gene. The 86 edited embryos were not implanted, but used to evaluate the specificity and safety of the technique: 71 survived the manipulation and 54 had corrected sequences. The scientists also documented unintentional mutations. The reaction was swift within the US with National Institute of Health (NIH) director, Francis Collins, saying that it is unethical to insert or modify sequences in the germline when you don't know the full consequences (Petre, 2015).

Genetic engineering is taking on the challenge of finding ways to improve human functioning and relieve suffering. Critics caution that some things will go wrong in the beginning. Pragmatism leads us to take risks, favoring experimental therapies that follow the trajectory of scientific evidence in cellular and animal model systems. The initiative to 'do something about it' rather than complain or leave the suffering to their fate, is to be proactive. Scientists and physicians who aim for new goals have to be brave as they enter new, potentially dangerous waters, as those who developed the first vaccines were. Testing new therapies in a series of controlled clinical trials is the path to new drugs and therapeutics.

Somatic cell gene therapy has an imperfect record in gene therapy. Clinical trials aimed at relieving symptoms by delivery of the missing gene or malfunctioning protein have achieved notoriety when they have failed and when they have succeeded (Misra, 2013). In a normal process, a new technique is evaluated in an animal model, goes through a series of clinical trials for safety and efficacy and is then adopted in standard practice. When in vitro fertilization (IVF) became a way to help infertile couples bear children, the UK established national guidelines for its use, but in the USA, no universal healthcare system exists and no guidelines were established. The consequence was that IVF clinics multiplied in the private sector, making access to the technology unequal. The current cost of one cycle of IVF is \$12,400 (about 22% of the average household annual income). If gene editing with CRISPR follows a similar path into private IVF clinics, the cost will select only the wealthy as potential clients. Correcting what Francis Collins refers to as "typos in the book of life" leads one to imagine that "editing" is an ordinary therapeutic tool. Everyone wants genetically healthy children but dare we assume what qualifies today will suit the posthuman? (Boyd, 2017).

Porter posits a values problem for transhumanism which concerns how current humans and future posthumans will value health, "normal" intelligence, and longevity. Pointing to the potential conflict over values, would it be possible to maximize beauty and equality simultaneously? "Transhumanists would use technology, or allow and encourage individuals to use technology, to

make everyone equally beautiful – but this utopian transcendence of the contrastive nature of beauty and equality vis-à-vis each other is conceptually incoherent” (Porter 2017). How will beauty be recognized if all possess it?

Technology is by design and intent for the use of people, for their benefit (Boyd 2016). Human becoming is a way that humans express creativity, but technology per se does not have its own becoming innate to itself. Humans become but technology does not. Technology changes through human action, therefore humans are the agents of change. Technology demonstrates our relationship with the world, reflects our desires, will, and values. Robotics, nanobots, gene editing, all intended to improve or enhance humans hold great hope for improving the length and quality of our lives. It is also possible that technology is a means to the will to power, unknown whether it will be used for good or ill effect (Boyd, A. 2017).

### Conclusions

What is at stake is a new understanding of what it means to be human. By the second half of this new century, there may be no clear distinction between human and machine intelligence. On the one hand, we might have biological brains vastly expanded through distributed nanobot implants. On the other hand, we could have fully nonbiological brains that are copies of human brains, albeit also vastly extended. And we will have a myriad of other varieties of intimate connection between human thinking and technology it has fostered say the transhumanists.

To do what we ought is a universal challenge for humans. It is evident to our moral natures that seeing a poor person begging for food or a sick person pleading for health care or a refugee seeking a safe place to live that those people are our neighbors, no more and no less human than we are. When we experience others coming into our presence bearing legitimate claims on us, how we treat them is a testament to our morality and common humanity (Boyd, 2014).

Bioethicists responses should include the following: Justice requires procedures that allow all social members to participate – to have access to basic human goods necessary for life, well-being and the society in which we live – to share relationships among peoples and cultures. Taking a relational view of human nature as a dynamic and forward moving effort, humans can transform nature and depend on it for their life. The common good is reinforced by the virtue of solidarity and the care for those marginal in any society. Transhumanism tends to speak of the person mechanistically, suggesting that better bodies, longer lives, super intelligence, moral enhancement can be manipulated at will. It is true that we face global problems that need collaborative and cooperative solutions. This world and all who live in it matter. This is affirmed by unity in diversity. In essence, we should learn to be human before we seek to be posthuman.

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## Perspectives on the Ethics of Maternal Somatic Support

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### Abstract

Maternal somatic support after brain death occurs when a brain-dead patient is pregnant and her body is kept alive to deliver a fetus. The moral controversy cracks into two different extreme parties which one praised the worthiness on the dignity of dying mother and the other insists the rights to life of the unborn child. In other words, the moral status of the brain-dead mother and that of the fetus are of ethical question. This paper aims to resolve the conflicting point-of-views in the matter of maternal somatic support, suggesting that the key factor should be placed on mother-child relationship rather creating a separated clash between the two.

**Keywords:** maternal somatic support, brain-dead, rights to life, dignity, moral status

### 1. Introduction

Cases of brain-dead pregnancy<sup>1</sup> have been reported from time to time on the news worldwide. For instance, in October 1992 a young woman died in a car accident. She was 13 weeks pregnant and her fetus appeared to be unhurt, so a decision had to be made: should the mother's body be artificially supported in order to give the fetus a chance to live? (Anstötz, 1993). Similar cases can be found worldwide. Masaki et.al (2016) summed up brain-dead pregnancy cases occurring. For instance, in Japan, three brain-dead pregnant women's cases were reported in 2014. It was reported that these women were brought to a university hospital and became brain-dead. Two of the three women had delivered their babies. One family wanted to save the fetus, the other remained uncertain until the contraction of the woman began, and the third had no desire for the baby in the first place. In Canada, a Canadian woman was just 22 weeks pregnant when she was declared brain dead. Doctors in charge kept her alive at her husband's request so that their unborn baby would have a better chance of survival. She was on life support for six weeks before she gave birth to her child. In Hungarian, the woman was 15 weeks pregnant and she was on life support for 3 months before she delivered a healthy baby boy. In the USA, a pregnant woman who lapsed into a brain-dead state was removed from life support after a hospital complied with a judge's order to disconnect her from the machines keeping her alive. Her husband wanted to have his wife die with dignity. The fetus, which was at 23 weeks' gestation, was not delivered.

Up to recently, "brain-dead" has been the medical criteria to announce one's legal death<sup>2</sup>. Yet announcing that one died according to this criterion raises a number of the controversies beyond simply those of organ donation. In the case of brain-dead pregnancy, the issue becomes more complicated. Should we regard that the mother donates her womb to the fetus? While in the case of organ donation, one might indicate one's preferences, should we assume that the mother would indicate her willingness to save her baby? What if the mother has no preference at all? Does exercising somatic support to maintain the life of the fetus morally impermissible?

The moral controversy ranges from two different extremes – one which praises the worthiness on the dignity of dying mother and the other insists the rights to life of the unborn child. In other words, the moral status of the brain-dead mother and that of the fetus are in conflicting situation. This paper aims to clarify the conflicting point-of-views in the matter of maternal somatic support or brain-dead pregnancy through the criterion of moral status.

### 2. Using the Mother as a Means

The central argument against the practice of somatic support in the case of brain-dead pregnancy would go something like this:

(1) It is morally wrong to use one as a means<sup>3</sup>.

(2) The practice of somatic support on brain-dead pregnancy uses the mother as a means to the fetus's end.

(3) Therefore, it is wrong to practice somatic support on brain-dead pregnancy.

The supporters of the practice of somatic support would deny the second premise of this argument. So it is on whether or not the mother is merely used as a means to achieve the fetus's end. The issue is more complicated because, unlike organ donation where the relationship occurs between two unrelated individuals, brain-dead pregnancy involves the mother and *her* baby, two people of the same blood. This difficulty reminds us of some similar discussions in the abortion case but the difference is that in abortion, the mother can express her rights on her own body because she is alive while in the brain-dead pregnancy, the mother cannot speak. In other words, the presence of the mother is the critical point in the discussion.

Hilde Lindemann Nelson, an American philosophy philosopher and bioethicist gives an interesting ingenious analogy, comparing the mother as an architect in her pregnancy. Basically, she compares it to the famous distinction between the architect and the bee from Marx that the woman's activity of being pregnant is thought to follow its own preordained patterns like the bee. With this common view, the pregnant woman cannot help what she is doing. This would also be following the biological imperative for survival, as

<sup>1</sup> The first successful attempt to bring a postmortem pregnancy to term is generally taken to be the American one reported by William P. Dillon and colleagues at Buffalo, New York, in February of 1981, a case in which a 26-week-old infant was delivered 5 days after its mother was pronounced brain dead.

<sup>2</sup> The definition of brain-death is sometimes defined inconsistently, but on majority, one follows the Harvard criteria of brain-dead or based on medical indications.

<sup>3</sup> Using "one as a means" here can basically sum up the major controversies on the mother including dying with dignity and the right of the dead.

discussed in the *Selfish Gene* (Dawkins, 1976), or the love of life (Macer, 1998).

Nelson believes that such a picture is false because “*its persistence both testifies to and reinforces social attitudes toward women that are demeaning*”<sup>4</sup> because human pregnancy is no more purely biological than any others human activities. She narrates as follows, “*As is typical for her species, she both obeys the laws of nature and improves upon them, ordering and shaping what she finds in the natural world through her own intentional, creative activity. She transforms natural processes by valuing them or by imbuing them with meaning out of the ordinary phenomenon of hunger, for example, she creates a dinner party. That is, she turns the need for food into an occasion for expressing friendship, or possibly furthering social ambition. Like the architect’s, her edifices can be and often are purposeful and deliberate.*”<sup>5</sup>

Nelson finely argues four ways<sup>6</sup> that a woman is rather an architect rather than a bee after having conceived:

(1) Unlike other animals, women often are pregnant or conceiving for a *reason*: they may conceive and carry a fetus because they want a special relationship that will last over time. They might want an existing child to have a sibling, a partner to play with or because without children they would feel the family is not complete. In some special case, they might hope the baby’s bone marrow will be a lifesaving match for a dying family member.

(2) Once having conceived, the *purposiveness* continues that the woman creates a relationship with her fetus. She might feel at odds with her own body or having a special harmony with it when belly gets bigger day by day since she might still regard this fetus as being or not being part of her own self. She can make decision on either giving up (as in the case of abortion and rape) if she feels intrusion or embraces the loving relationship with the fetus since the beginning. Moreover, unlike outsiders (the father, grandparents, siblings...) can know the experience of the child from her own inner perspectives

(3) Pregnancy is a *creative* and *purposeful* process. Through the deliberation in (1) and resistance/acceptance in (2), pregnant woman is also actively doing something in the present moment for the fetus she carries with hospitality. For example, she has a duty to restrain from smoking, drinking, taking drugs and so on. In all these ways, the sheltering act of human pregnancy carries with it a *responsible* and *well-recognized* moral significance.

(4) Like an architect who firstly, got constrained by the law of nature (e.g. obeying the law of nature, building houses that refrains from earthquakes or flooding and such) and secondly, got refrained from the social forces in their profession (through their education and society they work), a pregnancy woman creates purposefully within a biological and social context. She, obeying the law of nature, carries the pregnancy to full-term, technically 40 weeks and cannot be hurried with all acceptances on her body and hormones changes. She

also conforms to the societal values where she lives regarding how she lives, thinks, acts and carries her pregnancy.

Nelson comes to a conclusion that the presence and experiences of women before, during and after pregnancy is a significant factor that signifies the human element of bringing a baby to term, not barely rely upon mechanical or pharmacological mimicry of what a biological pregnancy should have been. She sums up that postmortem pregnancy is “creepy” because it exaggerates a false model of pregnancy that “it is the image of the women as passive, as unconscious, as instinctively rather than deliberately nurturing”<sup>7</sup>.

Is Nelson’s argument sound? If we closely examine the four processes that Nelson has nicely narrated about a woman’s experience of to conceive, to conceiving and coming to term, we can now draw out a fact that the woman accepts the fact that pregnancy is a purposeful planning and accepted process. It is rather an internalized process, which women overcome to finally get to a stage of harmony and results in a responsible treatment over the fetus. Nonetheless, Nelson’s conclusion rather tells us that because the mother is absent, the postmortem pregnancy or any pregnancy that there is no presence from the mother should be terminated. The external circumstance that endangers or brings out the termination of the pregnancy has spoiled all the efforts that the mother has build during the past 40 weeks. Because the mother is no longer able to make a purposeful decision does not entail that she does not want the fetus to carry to term. Hence, while Nelson made a presumptuous conclusion on the case, and unless she has clearly indicated her involuntariness through either in written documents or verbally in continuing the pregnancy to term, we have a relatively sounder assumption to derive the women’s will in continuing the pregnancy. The fact is that the woman does not choose to abort at any point before the tragedy occurs.

### 3. The Value of the Fetus Life

On the contrary, the supporters of the practice of somatic support on brain-dead pregnancy usually voices that comparing to a mother who is to be considered as a “cadaveric incubator”, the fetus’s life is more precious for that there is the potentiality to be survive. Moreover, it is claimed from a medical point-of-view that it is acceptable to strive to resuscitate the fetus by maintaining life support if there is a reasonable chance the pregnancy will continue at least until fetal lung maturity is achieved (Fadel, 2011). Similarly, from the principle of beneficence, physician shall act for the best interests of the patients. There is a corresponding practice in real practices that physicians must primarily focus on saving the life of the fetus, and that therefore the treatment protocol should give special recommendations on how to support the mother in a way that she can deliver a viable and healthy child (Esmaeilzadeh et.al. 2010).

From the supporters’ viewpoint, it is the life of the fetus is more valuable than the life of the brain-dead mother. That is being born is better than being unborn

<sup>4</sup> Hilde Lindemann Nelson, 1994, “The Architect and the Bee: Some Reflections on Postmortem Pregnancy”, *Bioethics* 8(3), p.262

<sup>5</sup> *Ibid*, pp. 262-263

<sup>6</sup> *Ibid*, pp. 262-266

<sup>7</sup> *Ibid*, p.266



or non-existence. One would straightly recall about traditional religious viewpoint especially in Christianity that life begins at the point of conception. Nonetheless, it should be noted that such argument is already rejected by current philosophical viewpoint when discussed about abortion.<sup>8</sup> Still, the abortion discuss is not of any help in the discussion of the practice of somatic support in brain-dead pregnancy because for the former, the underlying line can set out criteria of moral status whether an embryo or fetus is a (human) person while in the latter, the fetus has reached the last stage of pregnancy or maturity.<sup>9</sup> Therefore, based on the same criterion, the fetus in the case of brain-dead pregnancy, it is entitled with moral status. Yet it appears that even if the fetus gains moral status, the controversy on the practice of somatic support remains.

How should we then look upon the matter of maternal somatic support? In addition to the willingness of the mother, a medical indication that the neonate would survive healthily should also be of consideration. From the principle of beneficence, physicians must primarily focus on saving the life. In the case of maternal somatic support, that life is that of the fetus. Erlinger (2017) conducted a literature review on forty-three pregnant patients, who were in a permanent vegetative state, are brain dead, or in a coma, 1976-2015. The result shows that for the neonates, the optimal period for delivery a viable and healthy infant in a normal pregnancy is 32 to 34 gestational weeks. Prior to week 24, the neonate would have a 20% to 30% chance for survival, with 40% probability of severe neurological disorders. The prognosis improves for neonates delivered between weeks 24 and 28, when the survival increases to 80%, and the risk of neurological complications is 10%. After gestational week 32, the risk to the life and health of the fetus is the lowest, with a 98% survival rate and less than a 2% risk of neurological complications.

### Conclusion

In conclusion, it has been demonstrated that the focus of the discussion is placed on the *relationship* between the mother-fetus, rather than as two distinct individuals. The previous discussions on the brain-dead pregnancy try to break the two agents into two separated unrelated persons. More than this, the discussions place largely biased perspectives, taking side and overlooking the critical and special component in a mother-child or family relationship. Realizing this key point enables us to look for in-depth into the issues of brain-dead pregnancy. The question is no longer about the women's dignity, their rights after death, and the fetus's rights to life or whose value of life is more worth than the other. It is rather about the willingness of the mother and how the medical indications reveal the circumstances, so as how

would we shape our perspective into a right manner.

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## Pakistani Parents Understand Informed Consent but not Assent: A Pilot Study

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### Abstract

**Background:** Informed Consent should be considered as essential part of clinical practice in adult as well as in pediatric settings. The scenario of informed consent in pediatric clinical settings varies because minors are legally considered incompetent to provide decisions that have legal bindings regarding healthcare.

**Research Objectives:** The objectives of this study are to (i) understand the importance of Informed Consent for Clinical Treatment in Pediatric settings from parents perspective; (ii) explore the current practice of Informed Consent(IC) obtained for clinical treatment in Pediatric setting of developing country hospital(s) (iii) identify factors associated with the practice of obtaining IC; and (iv) recognize involvement of child in decision making process i.e. assent.

**Research Design:** This is Descriptive Exploratory Single Center study that reveals inadequacies in the process of informed consent in pediatric settings. Data was obtained from parents of pediatric patients

<sup>8</sup> For the arguments on abortion, See Peter Singer, 2011, "Taking Life: The Embryo and Fetus" in *Practical Ethics*, Third Edition, (New York: Cambridge University Press), pp.123-154

<sup>9</sup> At what point, technically at what term or week of pregnancy, should the physicians practice the somatic support is still lacking of empirical data. See Lisa Rose Erlinger, 2017, "Guidelines for Supporting a Pregnant Patient with Brain Death: A case discussion and literature review", *Journal of Nursing Education and Practice* 7(8): 86-92

admitted in pediatric intensive care unit for at least 24 hours Data was obtained from 128 participants.

**Ethical Considerations:** The research was approved by institutional ethics review committee and verbal informed consent was obtained from all study participants. All parents who agreed to participate in research were assured that their responses would remain confidential and would not affect their child clinical treatment in any way.

**Findings:** Most participants were satisfied by current informed consent process. 89% (n=114) of parents disagreed over involvement of child in decision making process for clinical treatment i.e. assent.

**Discussion:** Previous studies done in Pakistani context on adult population reveals inadequate process of informed consent and level of illiteracy, language barrier, insufficient time provision for signing informed consent, poverty, power deferential and oppressive mind as factors hindering meaningful consent.

**Conclusion:** Our pilot project suggests general satisfaction of parents with current process which raises three important questions i.e. are we getting better? Is pediatrics different than adult? And are parents satisfied with an inadequate process?

**Key Words:** Informed Consent, Pediatrics, Bioethics, Assent, Pakistan

## Introduction

Informed consent is a process grounded in the notion of respect for person. In medical practice, the concept of informed consent is concentrated on the principle of autonomy where an adult individual makes a decision for himself by choosing best of the accessible possibilities (Beauchamp & Childress, 2001). It is right of an adult to make informed decisions regarding their life and about medical treatment, for this reason informed consent is administered by Health Care Professionals (HCPs) to a competent adult patient that enables them to act in accordance of informed choices.

The scenario of informed consent in pediatric clinical settings varies because minors are legally considered incompetent to provide decisions that have legal bindings regarding healthcare. Parents have the legal and moral authority to make medical decisions on behalf of their children as their Surrogate Decision Makers (SDM) for several reasons (Diekema, 2004). Parents are considered to make best decisions for their child as they care for them, know the needs of child and protect their children from harm (Unguru, Pediatric decision-making: informed consent, parental permission, and child assent, 2011). However, the right of parents to act as SDM for their child is not right centered on principle of autonomy rather it is an obligation of parents to provide appropriate medical care to their child. According to Beauchamp & Childress 2001, only parenthood doesn't make one qualify for acting as SDM for their child. SDM must meet the four pre-requisites i.e. (i) be competent to make reasoned judgements; (ii) possess adequate knowledge and information; (iii) be emotionally stable and; (iv) be committed to the incompetent patient's interests (Fisher-Jeffes, Barton, & Finlay, 2007; Unguru, Pediatric decision-making: informed consent, parental permission, and child assent, 2011; Hall, Prochazka, & Fink, 2012).

Pakistan is categorized as low-to-middle income developing country with an annual per capita income in dollar terms has reached to US \$1512 in 2014-2015 (Highlights of Pakistan Economic Survey 2014-2015, 2015). Population census illustrates Pakistan as world's 6<sup>th</sup> largest populous country with population estimate at 191.71 million (Wikipedia, 2016). As per UN 2015 report 35% of the total population belongs to age group of 0 to 14 years, 58.4% are 15 to 59 years, and 7.2% are over 60 years of age (Population Division of the Department of Economic and Social Affairs of the United Nations Secretariat. World Population Prospects, 2015). The average number of people per family is 6.8, and almost 17.2% people live below the poverty line (Bajwa, 2013). The average life expectancy for men and women is 63 and 67 years respectively (UNICEF; Pakistan Statistics, 2013). In Pakistan, the decision making process is inculcated in family centered approach and community based society. Extended families i.e. three or more generations are seen residing in the same house (Moazam, 2000). In addition, hierarchal and patriarchal system is followed where eldest male or earning male of the family makes decisions for women and other family members and following of their decision is expected. Physicians are generally seen as angles or heavenly creatures and one that is sent by God to help them in difficult situations and are trusted, respected for authority and feared (Khan, 2008). Literacy rate is 55% (Literacy Rate of Education in Pakistan 2016, 2015) with masses having no concept of individual rights. Overall, the approach used for decision making process is paternalistic rather autonomous approach (Corrigan, 2003). The concept of informed consent essentially demands shifting from paternalistic approach to autonomous approach.

Several studies have been done that investigates the process of informed consent in pediatric research settings (Pate, 2013). However, there is poor, if any, published information about the process of informed consent used for clinical treatment in pediatric settings especially in hospitals of developing countries and discussion is far from being considered by society. There is significant need to understand the phenomena of obtaining informed consent in pediatric clinical settings to reduce the risk of exploitation and protection of vulnerable population which in this case is pediatric. This pilot study reports on a descriptive exploratory likert scale responses of parents of pediatric patients, to explore existence of IC form, process and policy for clinical treatment in Pediatric setting in developing country hospital(s); the importance of IC for clinical treatment in pediatric setting will be investigated; current practice of obtaining IC will be discussed at greater length; the knowledge that parents have of clinical treatment for which IC was obtained will be assessed; individual and professional attributes will be explored that are associated with the practice of IC for example understanding, language barrier, hierarchy, power differential, gender differences, and cultural influence; and lastly, parent's reflection over involvement of child in clinical decision making process in the form of assent will be discussed. The objectives of this study are to (i) understand the importance of Informed Consent for Clinical Treatment in Pediatric

settings from parents perspective; (ii) explore the current practice of Informed Consent (IC) obtained for clinical treatment in Pediatric setting of developing country hospital(s) (iii) identify factors associated with the practice of obtaining IC; and (iv) recognize involvement of child in decision making process i.e. assent.

### Methodology

This study evolved out of a larger study, *"The project on understanding current practice of informed consent in pediatric clinical settings of developing country hospitals"*, which aimed to describe and understand the informed consent process from perspective of parents of children admitted in pediatric hematology-oncology intensive care unit and healthcare providers working in pediatric clinical settings. This is Descriptive Exploratory Single Center study in which data was obtained from parents of pediatric patients admitted in pediatric intensive care unit for at least 24 hours. Parents of those children who were admitted in pediatric intensive care unit were participant in this study. Parents who have an experience of giving informed consent at least once during their child's current stay at hospital were included in study. Parents who did not give informed consent for any procedure and those who refused to participate in study were excluded. Sample size and subject selection for parents was determined as convenience sample to provide data, generate hypothesis and refine the measurements for a more comprehensive study. Potential participants were approached by the data collector, who explained the study and offered participation. Immediately after obtaining informed consent for research participation, parent was offered likert scale questionnaire by research officer. A survey was completed during the child's inpatient admission or in outpatient pediatric clinics. The research was approved by the institutional ethics review committee and verbal informed consent was obtained from all study participants. All parents who agreed to participate in the research were assured that their responses would remain confidential and would not affect their child clinical treatment in any way.

### Instrument and key measures

An extensive literature search revealed absence of an instrument for obtaining data required for this study therefore; a pilot study was designed in which quantitative instrument i.e. likert scale questionnaire were developed and tested simultaneously for its validity and reliability. This instrument was used to elicit data and provide data regarding informed consent process experience of parents who recently or in past provided informed consent for clinical treatment of their child. Socio-demographic data including age of parent and child both, gender, ethnicity, socioeconomic status, education level, language barriers and purpose of obtaining informed consent was obtained via brief pre-interview questionnaire which was followed by administration of likert scale questionnaire (see Table 1). Data collector and language translators administered quantitative instrument to those participants who were unable to read, write, speak or understand both the languages. The likert scale was comprised of 12 items

focused on identifying parent's understanding about the process of informed consent, comprehension, process, voluntariness, their satisfaction with current process and involvement of child in decision making process. A 5 point scale consisting of 'strongly disagree, disagree, don't know, agree and strongly agree' was used. The instrument was initially developed in English and translated in Urdu. Respondents were also asked to comment on content and flow of survey questionnaire. Questions that were marked as difficult to understand correctly were discussed, revised and pilot tested again. The questionnaire was finalized after evaluation of all questions clarity and comprehension.

### Results:

#### **Demographic and Socio-Economics:**

Data was obtained from 128 participants for pilot testing from single center. Overall there were 112 male and 16 female participants (M:F = 7:1). Mean age of participating parent was 45.35 years (SD: 8.875, range 28 - 69). Although, we wanted to have equal representation from both gender for the purpose of data collection but most of women did not agree to participate in our survey and they deferred us to male head of household. The mean age of child for whom IC was obtained from parent was 7.45 years (SD: 4.058, range 2 - 15). 45 children were female and 83 were male. The sampling technique was convenient therefore; equal representation of child gender was not achieved. The group had equal representation from all ethnic origins, out of 128 research participants 13 (10.2%) were Sindhi, 39 (30.5%) Punjabi, 52 (40.6%) Pashtun, 14 (10.9%) Balochi, 6 (4.7%) Saraki and 4 (3.1%) Muhajir. Socio-economic data shows mean monthly income of parents 21350 Pakistani Rupees which is equivalent to USD 203.86 and the mean total number of family members as 8.55. Monthly income per capita in Pak Rupees was also calculated for each household. 26 families (20.3%) fall under <1500, 45 families (35.2%) were in bracket 1501 - 2000, 27 families (21.1%) between 2001 - 3000 and 30 families (23.4%) above 3000 monthly income per capita in Pak Rupees (USD 1 = Rs. 105). Satisfaction of parents with informed consent was not related to education level. Satisfaction of parents with informed consent was not related to ethnicity and monthly household income per capita. Level of education in research population was 15 (11.7%) illiterate, 27 (21.1%) have studied <10 grade, 33 (25.8%) had completed 10<sup>th</sup> grade, 35 (27.3%) had completed 12<sup>th</sup> grade, 11 (8.6%) were undergraduate and 7 (5.5%) were having postgraduate qualification. Impact of level of education on understanding informed consent was not found to be significant (see Table 2: Demographic and Socio-Economic Data).

#### **Consenting person:**

To examine parental shared decision making model existence in Pakistani context the research group was asked specifically regarding the consenting person on behalf of child with options mentioned as father, mother, both father and mother, and any other. Our study illustrated that informed consent in pediatric clinical settings was mostly given and signed by patient's father i.e. 97 (75.8%), 31 (24.2%) by mother and 0 (0%) by

**Table 1: Informed Consent Survey Questionnaire for Parents**

**a. Demographic data**

<b>1. Date:</b>		<b>2. Participant identification number:</b>			
<b>3. Age of parent:</b>	<b>4. Age of Child</b>	<b>5. Gender of parent</b>		<b>6. Gender of Child</b>	
		<input type="checkbox"/> Male	<input type="checkbox"/> Female	<input type="checkbox"/> Male	<input type="checkbox"/> Female
<b>7. Race/ Ethnicity</b>					
<input type="checkbox"/> Sindhi	<input type="checkbox"/> Punjabi	<input type="checkbox"/> Pashtun	<input type="checkbox"/> Balochi	<input type="checkbox"/> Saraiki	<input type="checkbox"/> Muhajir
<input type="checkbox"/> Other, _____					
<b>8. Socioeconomic status</b>					
<input type="checkbox"/> Monthly income: _____			<input type="checkbox"/> Total number of family members: _____		
<b>9. Education level</b>					
<input type="checkbox"/> Illiterate	<input type="checkbox"/> < 8 <sup>th</sup> grade	<input type="checkbox"/> 10 <sup>th</sup> grade	<input type="checkbox"/> 12 grade	<input type="checkbox"/> Undergraduate	<input type="checkbox"/> Postgraduate or above
<b>10. Relationship with patient</b>					
<input type="checkbox"/> Father	<input type="checkbox"/> Mother	<input type="checkbox"/> Brother	<input type="checkbox"/> Sister	<input type="checkbox"/> Uncle	<input type="checkbox"/> Aunt
<input type="checkbox"/> Any other, _____					
<b>11. Consent was obtained from</b>					
<input type="checkbox"/> Father	<input type="checkbox"/> Mother	<input type="checkbox"/> Both father and mother		<input type="checkbox"/> Any other, Specify relationship: _____	
<b>12. Language you speak and understand (select all applicable)</b>					
<input type="checkbox"/> English	<input type="checkbox"/> Urdu	<input type="checkbox"/> Sindhi	<input type="checkbox"/> Balochi	<input type="checkbox"/> Punjabi	<input type="checkbox"/> Pashtu
<input type="checkbox"/> Any other, _____					
<b>13. Language in which informed consent was obtained (select all applicable)</b>					
<input type="checkbox"/> English	<input type="checkbox"/> Urdu	<input type="checkbox"/> Sindhi	<input type="checkbox"/> Balochi	<input type="checkbox"/> Punjabi	<input type="checkbox"/> Pashtu
<input type="checkbox"/> Any other, _____					
<b>14. Informed consent was obtained by</b>					
<input type="checkbox"/> Doctor	<input type="checkbox"/> Nurse	<input type="checkbox"/> Both	<input type="checkbox"/> Any other, specify _____		
<b>15. Purpose of informed consent (select all applicable)</b>					
<input type="checkbox"/> Surgical procedure	<input type="checkbox"/> Mechanical Ventilation	<input type="checkbox"/> Chemothe-- rapy	<input type="checkbox"/> Invasive diagnostic procedures	<input type="checkbox"/> Other: _____	

**b. Likert Scale**

<b>1. As per my understanding obtaining informed consent is moral requirement.</b>				
<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Don't know	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree
<b>2. As per my understanding obtaining informed consent is legal requirement.</b>				
<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Don't know	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree
<b>3. An informed consent should be obtained for treatment/procedure.</b>				
<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Don't know	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree
<b>4. I think it was important to obtain informed consent from me.</b>				
<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Don't know	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree
<b>5. I was able to get copy of informed consent form after signing for my record.</b>				
<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Don't know	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree
<b>6. I was able to understand information provided to me completely.</b>				
<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Don't know	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree
<b>7. I was able to understand the treatment/procedure that they wanted to perform on my child.</b>				
<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Don't know	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree
<b>8. I think informed consent was necessary to obtain for said procedure.</b>				
<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Don't know	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree
<b>9. I was satisfied by the time given to me for explanation of procedure/treatment.</b>				
<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Don't know	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree
<b>10. Enough time was provided to me for making decision and signing informed consent form</b>				
<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Don't know	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree
<b>11. I gave informed consent voluntary without any coercion of influence.</b>				
<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Don't know	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree
<b>12. I involved my child in decision making process with me.</b>				
<input type="checkbox"/> Strongly disagree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Don't know	<input type="checkbox"/> Agree	<input type="checkbox"/> Strongly agree

**Table 2: Demographic and Socio-economic Data**

Variable	Frequency (%)
<b>Age of parent</b>	
18-35 years	7 (5.46)
35-50 years	91 (71.1)
50 and above	30 (23.43)
<b>Gender of Parent</b>	
Male	112 (87.5)
Female	16 (12.5)
<b>Age of child</b>	
0-2 years (Infancy)	8 (6.25)
2-5 years (Toddler)	45 (35.15)
6-12 years (School age)	57 (44.53)
13-18 years (Adolescents)	18 (14.06)
<b>Gender of child</b>	
Male	83 (64.84)
Female	45 (35.15)
<b>Race/Ethnicity</b>	
Sindhi	13 (10.15)
Punjabi	39 (30.46)
Pashtun	52 (40.62)
Balochi	14 (10.93)
Saraki	6 (4.68)
Muhajir	4 (3.12)
<b>Monthly income/Capita in Pak Rs. (\$1= Rs 105)</b>	
<1500	26 (20.31)
1501-2000	45 (35.16)
2001-3000	27 (21.09)
>3001	30 (23.43)
<b>Education level</b>	
Illiterate	15 (11.72)
<10 grade (below matric)	27 (21.09)
10 grade (matric)	33 (25.78)
12 grade (intermediate)	35 (27.34)
Undergraduate	11 (8.59)
Postgraduate	7 (5.46)

**Table 3: Practice of Informed Consent**

Variable	Frequency (%)
<b>Relationship of research participant with Patient</b>	
Father	112 (87.5)
Mother	16 (12.5)
Brother	0 (0.00)
Sister	0 (0.00)
Uncle	0 (0.00)
Aunt	0 (0.00)
<b>Consent was obtained from</b>	
Father	97 (75.78)
Mother	31 (24.22)
Both father and mother	0 (0.00)
<b>Language participant speaks and Understand</b>	
English	7 (5.46)
Urdu	128 (100)
Sindhi	13 (10.15)
Balochi	14 (10.93)
Punjabi	39 (30.46)
Pashtu	52 (40.62)
<b>Language in which IC was obtained</b>	
English	0 (0.00)
Urdu	128 (100)
Sindhi	0 (0.00)
Balochi	0 (0.00)
Punjabi	0 (0.00)
Pashtu	0 (0.00)
<b>IC was Obtained by</b>	
Doctor	96 (75.00)
Nurse	23 (17.96)
Both Doctor and Nurse	9 (7.03)
<b>Purpose of obtaining IC</b>	
Surgical procedure	34 (26.56)
Mechanical ventilation	47 (36.72)
Chemotherapy	18 (14.06)
Invasive Diagnostic procedures	29 (22.65)

**Table 5: Participant Responses to Assent with reference to Child Age**

Age Group	Total number of respondents (n=128)	Strongly Disagree	Disagree	Don't Know	Agree	Strongly Agree
Infancy (0-2 years)	8	0 (0)	8 (100)	0 (0)	0 (0)	0 (0)
Toddler (2-5 years)	45	0 (0)	42 (93.33)	0 (0)	3 (6.66)	0 (0)
School age (6-12 years)	57	0 (0)	52 (91.22)	0 (0)	5 (8.77)	0 (0)
Adolescents (13-18 years)	18	0 (0)	12 (66.66)	0 (0)	6 (33.3)	0 (0)

**Table 4: Likert scale response analysis**

Item	Strongly Disagree n (%)	Disagree n (%)	Don't Know n (%)	Agree n (%)	Strongly Agree n (%)
1. As per my understanding informed consent is moral requirement.	0 (0)	0 (0)	0 (0)	97 (75.78)	31 (24.21)
2. As per my understanding informed consent is legal requirement.	0 (0)	6 (4.68)	13 (10.15)	88 (68.75)	21 (16.4)
3. An informed consent should be obtained for treatment/procedure.	0 (0)	0 (0)	0 (0)	105 (82.03)	23 (17.96)
4. I think it was important to obtain informed consent from me.	0 (0)	0 (0)	0 (0)	107 (83.59)	21 (16.4)
5. I was able to get copy of informed consent form after signing for my record.	0 (0)	5 (3.9)	119 (92.96)	4 (3.12)	0 (0)
6. I was able to understand information provided to me completely.	0 (0)	0 (0)	0 (0)	89 (69.53)	39 (30.46)
7. I was able to understand the treatment/procedure that they wanted to perform on my child.	0 (0)	0 (0)	0 (0)	96 (75)	32 (25)
8. I think informed consent was necessary to obtain for said procedure.	0 (0)	0 (0)	16 (12.5)	77 (60.15)	35 (27.34)
9. I was satisfied by the time given to me for explanation of procedure/treatment	0 (0)	0 (0)	11 (8.59)	88 (68.75)	29 (22.65)
10. Enough time was provided to me for making decision and signing informed consent form.	0 (0)	0 (0)	13 (10.15)	61 (47.65)	54 (42.18)
11. I gave informed consent voluntary without any coercion of influence.	0 (0)	0 (0)	0 (0)	104 (81.25)	24 (18.75)
12. I involved my child in decision making process with me.	0 (0)	114 (89.06)	0 (0)	14 (10.93)	0 (0)

both mother and father which strengthens patriarchal approach in Pakistani context and discourages parental shared decision making model.

#### **Language Barrier:**

To examine a potential language barrier, all respondents were asked to select language(s) that they are able to speak and understand completely and language(s) in which informed consent was obtained from them as population of Pakistan has many diversified regional and local languages and language barrier is one the important factor that is frequently encountered in clinical practice while providing care to patients. The findings represented that all respondents were able to speak and understand their regional as well as national language. 100% respondents mentioned the language in which IC was taken and the language that they were able to speak and understand as same which in Pakistani scenario is Urdu.

#### **Purpose of obtaining Informed Consent:**

Data depicts that obtaining informed consent is routine practice of both doctors and nurses with 96 (75%) respondents choosing doctors, 23 (18%) selected nurses and 9 (7%) selected both doctor and nurse as one who obtained IC from them. Purpose of obtaining IC was diversified that included 34 (26.6%) for surgical procedure, 47 (36.7%) for mechanical ventilation, 18 (14.1%) for initiating chemotherapy and 29 (22.7%) for

invasive diagnostic procedures (see Table 2: Practice of Informed consent).

#### **Informed Consent Process:**

For each item, likert scale response 'strongly agree' and 'agree' indicates that proper procedure obtaining IC was followed whereas, 'strongly disagree' and 'disagree' depicts lack in the process of obtaining IC. Response 'Don't know' illustrates neutral opinion. Most of the participating parents reported that they found informed consent process helpful and were satisfied with current practice and process of obtaining informed consent that can be seen as 85%-100% research participant selected option agree or strongly agree against item 1, 2, 3, 4, 6, 7, 8, 9, 10 and 11. For item 5, 92.96% (n=119) of respondents selected don't know that depicts lack of insight about individual/patient/caregiver right. For item 12, 89.06% (n=114) of parents selected option disagree which demonstrates huge disagreement by parents on involvement of child in decision making process for clinical treatment or assent (see table 4: Likert Scale Response Analysis). This disagreement was common across all age groups i.e. 100% (n=8), 93.33% (n=42), 91.22% (n=52) and 66.6% (n=12) for age group infancy (0-2 years), toddler (2-5 years), school age (6-12 years) and adolescent (13-18 years) respectively (see table 5: Participant Response to Assent with Reference to Child Age).

## Discussion

The present study was designed with a purpose to assess the process of IC in critical care pediatric settings. Several factors complicate informed consent for pediatric clinical treatment in intensive care settings. The majority of parents that participated in the study were those whose child was admitted in pediatric intensive care unit with cancer as primary diagnosis which primarily compromises parent's ability to make informed and independent decisions as the news of cancer diagnosis itself is very distressing and patients as well as parents experience physical and psychological stress because of hospitalization (Pate, 2013).

This is especially problematic when there is a clinical urgency to initiate treatment that adds pressure on parents to make prompt decisions that have direct impact on life and death of their child. Moreover, as the settings in which their child was getting treatment was charity settings and most of the parents had affordability issues because of which they wanted their child to get care in respective hospital as the hospital works of philanthropic support and provides quality of care free of cost to these children. Health care facility affordability is an enormous issue in developing countries and therefore, admitting child in such facility than poses great challenge to parents autonomy as their decision might be coerced by fear of not getting treatment if refusal is made or affordability issues if they want to take their child to other hospital for treatment which may not be offered by this hospital.

Moreover, physician-patient power deferential and perception of doctors as divine creatures of God makes it even more difficult for patients to question physician judgment. Therefore, the component of voluntarism in developing country population cannot be assessed as an absolute feature as decision is driven and influenced by socio-economic determinants like poverty, illiteracy, and oppressive mind (Khan, 2008). Although these factors pose great challenges for application of informed consent in pediatric settings, the difficulties do not undermine its importance (Kodish, et al., 1998). The study found that parents (fathers) are satisfied with the current process of IC in pediatric settings. Whereas, previous studies done in 2006 and 2008 on adult Pakistani population showed inadequacies in the process of obtaining IC (Humayun, et al., 2008; Amin, et al., 2006). These findings raises three important questions i.e. are we getting better? Is pediatrics different than adult? And are parents satisfied with an inadequate process?

This study reports a very significant findings regarding absence of role of child in the informed consent process. The mean age of child was 7.45 years with range 2 years to 15 years and it was unanimous among parents that they did not involve their child in making decision related to their healthcare. Research suggests that an imbalance of power between adults and pediatric patients may provide additional stressors, especially if children are not allowed to participate in collaborative decision-making processes and are forced against their will to comply (Pate, 2013). Pediatric patients' decision making capacity should be assessed based on their ability to evaluate their medical condition and the consequences of the medical decisions made, and the power to make accurate and logical deductions.

Stages of childhood can be divided into three stages i.e. early childhood that includes infancy and toddler, middle childhood and adolescence. In early childhood, parents are fundamentally the only decision-makers and the involvement of child in decision-making process is not permitted. In middle childhood, even though, parents are the final decision makers nonetheless obtaining assent from child is important whereas informed consent is not required. In adolescence age group, assessment of patient's capacity is significant and involvement of adolescent patient in medical decision-making is ethically obliged to the extent appropriate to their capacity (Parsapoor, et al., 2014). Meaningful assent required an appreciation of the child's developmental stage and acknowledgment of his basic preferences. A child should be included in medical decisions to the extent that he or she is able to and wants to be involved. Parents and healthcare providers need to encourage children to communicate openly so that children may be actively involved in assent process (Unguru, 2012).

As this was a pilot study therefore the number of parents we studied was very small, which may limit the generalizability of findings. Furthermore, we studied only those parents i.e. fathers who agreed to participate. Also, this study reports findings of a single center which is private hospital. We believe that if this study will be conducted in government hospitals than the findings may be different because of diverse patient population and dissimilar approach/attitude of healthcare providers towards patients. It will also provide a contrast of practice of informed consent in government and private pediatric clinical settings. Future research must include more centers and larger numbers of parents of children who we enrolled as well as those i.e. mothers who declined to participate. Despite of these limitations the results reported by this study have important implications regarding informed consent for pediatric clinical treatment. The findings suggest that majority of parents are satisfied with the informed consent process. Our research demonstrates that ample amount of time was provided to parents to make decisions but we did not study whether ample opportunity was provided to them for asking questions and seeking alternative treatment.

The only factor that may mitigate this conclusion is the finding that 93% of parents reported that they don't know about having a copy of signed informed consent for their record. This finding also depicts that people residing in developing countries are either totally unaware or partially aware about their rights and same is true for patients and parents right in healthcare settings. This study was limited to exploring the current practice of informed consent in pediatric setting from parent's perspective which reports a high satisfaction. The larger study also focuses on exploring the current practice of informed consent from a clinician's perspective which literature has suggested to be a little problematic. Satisfaction alone doesn't guarantee/constitute adequate informed consent. Comprehension of information provided represents another important element of informed consent. The data reported here cannot address this issue because of small number of research participants and instrument design. Future

research must evaluate cognitive objectives of informed consent to assess more completely the adequacy of current practice. Analysis of level of education and income per capita in Pak rupees in our small cohort demonstrated no significant difference with regard to understanding of the information provided for informed consent. More research on assessing the impact of level of education and household income per capita on parents understanding of information for informed consent is necessary.

## Conclusions

Previous studies done in the Pakistani context on adult population reveals an inadequate process of informed consent and level of illiteracy, language barrier, insufficient time provision for signing informed consent, poverty, power deferential and oppressive mind as factors hindering meaningful consent barriers. Our pilot project suggests general satisfaction of parents with the current process which is gratifying, we remain concerned regarding the possible gap in comprehension, and acceptance by parents of information and process that is below international and ethical standards. Future research than must include more centers and large number of parents of children especially those mothers who refused to participate. More qualitative and exploratory research may identify significant factors that inhibit child involvement in decision making process by parents. Subsequently, investigating approach that is taken by parents in situations where there is diverging view point of parent and child over treatment options provided is essentially required. More research on the capacity and role of child in consent and assent for their clinical treatment is also necessary. Research on exploring approach of healthcare providers on involvement of child in decision-making process, investigate the quality of patient knowledge and understanding of information provided for obtaining informed consent, investigates the role of clinicians and their interactions with parents and children during the informed consent process and explicit research focused on the knowledge, attitudes, and use of assent by healthcare providers should continue. Lastly, it is essential to determine an effective, practical, and realistically applicable decision-making model in pediatric clinical settings.

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## Cybersecurity Challenges in the Implementation of a Hospital Management Information System

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### Abstract

**Background:** Hospital Management Information Systems (HMIS) have become an important part of a hospital's business process. The integration of HMIS with other vertical and horizontal health system elements is part of the roadmap of national health information system development (HIS). However, this integration has various risks in terms of cybersecurity like the case of the previous Wannacry Ransomware in several Hospitals.

**Method:** Literature review was used to obtain data and information about what risks of cybersecurity can occur to HMIS. Sources of literature used come from journals, articles and reports of cyberattack attacks from within and outside Indonesia.

**Results:** There are various forms of cyberattacks that can occur to HMIS including Phishing, Ransomware, DDoS (Distributed Denial of Service), and also internal data leakage. This security gap can interfere with business processes, patient safety, to lawsuits against hospitals if not anticipated.

**Conclusion:** Cyberattack threats can occur to hospital data through HMIS. A standard operational procedure is needed to monitor and evaluate HMIS to minimize the occurrence.

**Keywords:** cybersecurity, cyberattacks, HMIS, ransomware

## Introduction

The hospital as a work organization certainly needs a software to manage business processes in the form of Hospital Management Information Systems (HIS). The existence of HMIS is very helpful for stakeholders in managing various units within the hospital, from patient registration systems, medical record systems, laboratory information systems to billing systems (MoH, 2013). The types of HMIS, both free / open source and paid, face the same challenges, and need to be integrated (Alsafar *et al*, 2017). The integration of HMIS with other vertical and horizontal health system elements is part of the roadmap of national health information system development roadmap (HIS) (MoH, 2015).

HIS communication with various elements of the system through the internet is at risk to attack HMIS security. The Wannacry ransomware attack in early 2017 against several hospitals at Indonesia and other countries (Nangoy & Da Costa, 2017). In addition, patient electronic medical record data contained in HMIS has economic value for hackers. Electronic medical record data can be traded on the dark web for up to USD50 per patient (Filkins *et al*, 2016). This will certainly disrupt business processes up to a complaint of patients to the hospital.

Data security in HMIS is very important. This is because data security is related to medical records and confidentiality of patient data. Data security and medical confidentiality of patients has been regulated in the Regulation of the Indonesian Ministry of Health (MoH) No. 269 of 2008 on Medical Records, Health Minister Regulation No. 36 of 2012 on Medical Secret, Law No. 29 of 2004 on Medical Practices, Article 332 of the Criminal Code and Law Number 44 of 2009 on Hospitals. In addition, according to the Indonesian Medical Ethics Code year 2012, the confidentiality and patient medical data are very important. Therefore this publication will discuss cyber security threats like what can happen to HMIS and what should be done by the hospital to prevent it.

## Methods

This study uses a literature review method from journals, web articles and also cyberattack reports both from within and outside Indonesia in the last 2 years. Data from various sources of literature will be classified to consider what forms of cyberattack have the potential to occur against HMIS.

## Results And Discussion

In two years, the incidence of cyberattacks has increased. HealthcareITNews report states that up to August 2018 there have been 42 cases in 2018 (Healthcare IT News, 2018). While in 2017 there were 40 cases reported abroad (Healthcare IT News, 2017). Domestically reports on cyberattack incidents against hospitals, especially HMIS, were very limited such as ransomware and healthcare facility web defacing (Nangoy & Da Costa, 2017). The types of attacks that often occur against HMIS

can be in the form of Phishing, Ransomware, DDoS, and internal data leakage.

### Phishing

Phishing is a term from the word 'fishing', where hackers get control to access rights by utilizing system users' weaknesses or inaccuracies (Rajivan & Gonzalez, 2018). By obtaining this access control, hackers can enter the system then carry out activities such as data theft, data hostage, and data damage. One of the biggest cases occurred in July 2018 where 1.4 million patient medical record data at Unitypoint Meriter Hospital, Wisconsin were stolen by this method via email to employees. The email was taken over by the hacker after the employee was unsuspecting to click it. As a result hackers could enter the hospital system and steal data from March 4 2018 to April 3, 2018 (Davis, 2018).

### Ransomware

Derived from the word 'Ransom' and 'Software' is one form of a malicious program (Malware) which has the function of locking data to a system and then hostage it. Victims will get a message to pay a certain amount of ransom so that the data can be accessed again (Pope, 2016). In addition to Wannacry, there are several new types of ransomware that have the potential to attack health systems such as SamSam, OrangeWorm, and Petya. Losses caused by global Wannacry Ransomware are reported to be US \$ 500,000 in the form of ransoms and business process disruptions estimated at millions of dollars (Arjun, 2017). While Petya Ransomware has caused Merck pharmaceutical companies to lose US \$ 275,000,000 (Erman & Hussein, 2017).

### DDoS (Distributed Denial of Service)

DDoS is an action in the form of an attack on a system by sending insistent data until the system out of service (Ayala, 2016). Boston Children Hospital in 2014 experienced a DDoS attack on their website and new actors were caught in 2018. Although not directly about HMIS, DDoS attacks on the website have disrupted service activities and caused the hospital's loss of US \$ 300,000 (Departement of Justice, 2018)

### Internal data leakage

Employee carelessness in managing hospital data contributed to 7 out of 42 cases of medical data leakage in 2018 to September (Healthcare IT News, 2018). Leaks can occur intentionally such as misuse of data for sale, losing laptop or personal misuse.

In addition to the four methods above, a variety of new, more complicated hacking methods emerged. Hacking 1.5 million Singaporean health data in July 2018 is one form of complex, structured and planned hacking. The hacker enters the system gap and then implements the malware that works after the gap is closed. Malware works to duplicate data and then sends it to hackers from 1 May 2015 to 4 July 2018 (Tham, 2018). New methods such as Cryptojacking are predicted to target the health sector. Cryptojacking allows hackers to embed malware into servers with the aim of using the server to mine digital currencies (cryptocurrency). The impact is that the server will experience a decrease in

performance due to the additional burden of cryptojacking malware (Bloomberg, 2018).

Of the above cyber threats, patient health data is the key. Economic value and the impact of misuse of patient data can harm health services and patients. An ethical review requires health care providers to guarantee the privacy, confidentiality and security of patient data from those who do not have the right to access it. Even sharing data with third parties such as insurance requires patient approval first (Ozair *et al*, 2015). In addition to ethics, legal protection for patient data is also important to ensure the security of the use of information technology for health services. The United States of America has a regulation called Health Insurance Portability and Accountability Act (HIPAA) which regulates the security of personal health information (HHS, 2017). Europe has General Data Protection Regulation (GDPR) which also regulates the safety of patient data (EPF, 2018). While Indonesia has no specific regulations governing the safety of patient data. But implicitly there are regulations regarding the protection of personal data that are spread in several regulations such as population administration laws, information and electronic transactions laws to health laws and their derivatives (Hidayat, 2018 ; MoH, 2013). Also data security and stability and data sharing agreements are also implied in several regulations (Budiyanti *et al*, 2018)

Various forms of the cyber threat according to the Canadian Cyber Incident Response Center can be prevented up to 85% because it is impossible for an electronic system to be 100% safe (Ayala, 2016). Healthcare Information Management and System Society (HIMSS) recommends a standard operating procedure for hospitals to conduct cybersecurity testing periodically at least 2 times a year so that the system vulnerabilities found can be immediately patched (HIMSS, 2017). Whereas in terms of humans, improving knowledge of Cyberhygiene to hospital employees can reduce the risk of data leakage from within (Ayala, 2016). Routine data backup protocols and data disaster recovery planning (data disaster recovery) should also be prepared if a cyberattack occurs (Ayala, 2016).

## Conclusion

HMIS which is integrated with various elements of health has the potential to be susceptible to attacks that can eliminate, damage, or hostage patient data. Some threats that can occur are phishing, ransomware, DDoS to internal data leakage. Preventive actions such as cyberhygiene socialization, scheduling cybersecurity testing to disaster recovery data protocols can minimize the risk and impact of cyberattack on HMIS.

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## Role of Ethics in Hospitality and Tourism Industry

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### Introduction

Tourism is currently one of the top industries driving the global economy, with all countries having an increased opportunity to play a part either as the source market or the tourism destination. There is growing concern of ethics in both the hospitality and tourism industry as these professionals are faced with lots of ethical dilemmas in their daily operations. By nature, tourism industry products to a large extent depend on cultural and environmental resources. The industry involves activities that are continuously interacting with nature. Tourists' interest to visit different places leads to increased clearance of various natural areas for the purpose of developing hotels and resorts. Organic and solid wastes produced by the hospitality industry may contribute to environmental pollution.

In addition to the interactions with natural system, tourism activities involve both direct and indirect contact between local community and tourists. Like agro tourism and eco- tourism involve direct interaction whereas mass tourism has lesser direct involvement. In both situations, however contacts between host community and tourists cause various problems such as importation of new culture and lifestyle, over-commercialization of cultural commodities and conflict of values. Most of these problems are ideally ethical in nature as they lead to pollution, economic imperialism, environmental degradation, depletion of natural resources as well as sexual abuse.

As a result of these numerous ethical issues, there has to be a global acknowledgement of the need to think about the concept of sustainable or responsible tourism. Sustainable tourism: it is that which creates better places for tourists to visit and local community to live in. This form of tourism broadens the concept of sustainable or eco-tourism to include environmental, ethical and social considerations.

Responsible tourism: this form of tourism is related with all type of tourism that have reverence to the destination, cultural and natural environment and the interests of all involved parties. It will reduce harmful environment, social as well as economic impacts. And

will create more economical benefits for the host community and improving the overall interests of the destination.

Ethical principles include integrity, fairness, honesty, respect, attitude, leadership, accountability, loyalty and trustworthiness. Promoting these values in hospitality and tourism industry may cost some money in short term but they are likely to contribute to the long term success of the organization as well as the better future of the nation. Hospitality professionals is faced with an ethical dilemma of whether to give priority to profits or the customers. Ethics has a positive relationship with profits and overall success of an organization which will definitely help a country to move ahead in best economic condition. Creating a strong ethical environment in those sector can result in increasing a flow of the tourist from different part of world which leads a country to a successful destination and one of the greatest in the world.

### Conclusion

Ethics is essential in every aspect of life. Ethics will reflect the nature of the person as well as the organization. In the hospitality and Tourism sector, Ethics will play a vital role to lead the organization towards the successful way. Hospitality and Tourism industries are the best source of economy of the nation. It will drive the nation to the development, prosperity and peace. To build up and improve these industry, attitude and the behavior of the person who does involve on this sector is very crucial. For example, if the manager of the company leads the team with a good attitude, equality and respect to the fellow staffs then the outcome of the staffs will be productive which may keep the reputation of the industry will be high forever. Since the Tourism sector is one of the pillars as well as the vertebrate of the Nation in terms of the sources of economy, the ethical attitude and the behavior of the persons, attached with this sector will play an extreme role to guide it to greater success.

## Ethical Challenges of the Zika Epidemic

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### Introduction

Zika virus provides a case study for the intersection of science and ethics. The occurrence of formerly unreported cases of microcephaly following Zika infection of a pregnant woman caused the World Health Organization to declare Zika a global public health emergency in 2016. The virus was first described in 1947 and has caused sporadic outbreaks in Southeast Asia and several Pacific islands. The infections were described as mild febrile illness that were resolved by treating the symptoms.

Like other viruses in the Flavivirus family, Zika infection is primarily the result of a mosquito bite but is

distinct in causing Congenital Zika Syndrome (CZS). Reports from Brazil of microcephaly in neonates attracted attention and highlights several ethical concerns. Health care access, reproductive rights and care for children with disabilities are social justice issues. Newly developed experimental vaccines raises questions about testing in a challenge design or by recruitment of volunteers within the outbreak. The Zika pandemic raises many ethical questions, the two addressed in this paper are reproduction and vaccine related.

### Zika Virus

In 2015 a large outbreak of Zika virus occurred with cases of microcephaly in fetuses born to women infected during pregnancy. This was a new pathology not associated with other viruses in the Flavivirus family which includes Dengue, Chikungunya, Yellow Fever and West Nile Virus.

Zika was first isolated in 1947 from the blood of a rhesus macaque in the Zika Forest of Uganda. The first recognition of human illness caused by Zika occurred in Nigeria in 1953. The three cases were described as a mild febrile illness. A 2007 outbreak on the Yap islands resulted in an estimated 5000 infections within a population of 6700 (Duffy et al., 2009). Subsequent outbreaks in French Polynesia occurred in 2013 involving 32,000 persons. Zika virus infections were reported in other Pacific islands and Southeast Asia (Cao-Lormeau, et al., 2013).

Spread of Zika virus in the Western hemisphere was first reported in Brazil. The Ministry of Health estimated over a million suspected cases within the year and noted an increase in the number of infants born with microcephaly. Within five months, 4300 cases of microcephaly were documented and in retrospective studies, of French Polynesian health care professionals confirmed an increase in fetal abnormalities as well. Finding Zika virus RNA in the amniotic fluid and brain tissue of fetuses with microcephaly added confidence to the causal relationship between Zika virus infection of the pregnant woman, her fetus and the consequential birth defect (Rasmussen et al., 2016).

Zika is transmitted by *Aedes aegypti* mosquito and moves perinatally from mother to fetus. Subsequent analysis of blood and semen revealed the virus also may be transmitted person to person through sexual intercourse and blood transfusion. The first confirmed person to person case occurred in a patient in Rio de Janeiro, Brazil (Calvet et al., 2016). By the late spring of 2016, 61 countries had reports of locally acquired cases of Zika. In February 2016, the WHO declared Zika virus disease a public health emergency of international concern.

### Emergent virus

Zika may have emerged along with global increases in the spread of other Flavivirus, such as Dengue. Globalization and urbanization in an era of climate change contributes to more cases and an expanded geographical reach. Whether mutations in Zika contributed to microcephaly is a topic of current research focused on a better understanding of the full spectrum of clinical outcomes resulting from fetal Zika virus infection (Peterson et al., 2016)

In the “sylvatic cycle,” Zika virus circulates between non-human primates and the *Aedes* mosquitoes. The “urban cycle” features virus circulating between humans and domestic mosquitoes. Until 2007, Zika was confined primarily to the sylvatic cycle with rare human infections. The virus can transmit through at least 20 species of mosquito, and as such, the vector-borne spread encompasses the demographics of the vector. Zika’s recent epidemiological profile illustrates how rapidly mosquito borne virus can transition from local to global (Fauci and Morens 2016).

Zika virus evolution based on genetic relationship among isolates reveal two clusters, one representing the African lineage and the Asian lineage. The most sensitive diagnostic method is detection of RNA by Reverse Transcriptase – Polymerase Chain Reaction (RT-PCR). Viral RNA can be detected in the first seven days of the disease in serum and amniotic fluid (Mlakar et al., 2016). Molecular tests are more sensitive than antigen or antibody based tests but may not be readily available. Differential diagnosis of Zika from Dengue and other Flaviviruses can be done by Plaque Reduction Neutralization Titer (PRNT) assay and RT-PCR (Singh et al., 2016).

### Climate Change Impact

Global warming and climate changes have redefined the geographical distributions of important vectors of arthropod-borne viruses. The “Congenital Zika Syndrome” led WHO to declare the ZIKV epidemic a global public health emergency. Whereas other Flaviviruses may transfer from mother to fetus and cause preterm delivery and encephalopathy, Zika is the only virus of the group to be associated with microcephaly. Other viruses such as cytomegalovirus (CMV) and measles when acquired in vitro may also cause microcephaly (Chan et al., 2010).

#### Prevention and Control Strategies

Prevention and control of Zika virus is focused on vector control and protection from mosquito bite and person to person transmission. Vector control can be based on mechanical removal of standing water as breeding areas for female mosquitoes. Chemical control uses pyrethroids, organochloride or organophosphorus, compounds that are toxic to mosquitoes and other animals. N,N-diethyl-meta-toluamide (DEET) is an effective insect repellent safe for pregnant women. Plant extracts such as Citronella is an effective repellent. In work originally aimed at controlling Dengue, female mosquitoes infected with a *Walachia* parasite pass it in their eggs after mating with wild male mosquitoes and the next generation is resistant to Dengue and Zika viruses. The project, “Eliminate Dengue” has released mosquitoes in more than 40 areas in Australia, Vietnam, Indonesia, Colombia and Brazil. If shown to be environmentally safe and sustainable, the remaining question will be whether fewer infectious mosquitoes mean fewer human infections (Sevick, 2016).

### Vaccines

Developing a protective vaccine is a long process. Scientists are expanding efforts to create a vaccine against Zika following methods used for Dengue and Yellow Fever. Ideally vaccines should be protective

against infection known as “sterilizing immunity.” The first of three experimental Dengue vaccines to be licensed was the Sanofi Pasteur, Dengvaxia, a live attenuated Yellow Fever vaccine backbone with genes from Dengue virus four serotypes spliced into the Yellow Fever genome. It was administered to children in the Philippines and some of the children developed a severe form of disease, prompting questions about the safety of the vaccine. The little-understood phenomenon, antibody-dependent enhancement (ADE), is observed when a second infection by a different serotype of Dengue occurs and the person has antibody against the first serotype infection. Antibody to the first serotype can cross react with the second in a way that increases virus uptake in host cells leading to increased viremia and decreased immune clearance. Two groups working on other Dengue vaccines learned that it is important to determine if a person has antibody to any of the four serotypes before administering the vaccine. DENVax developed by Takeda is a Dengue serotype 2 genome with key genes from the other three dengue serotypes. TV003/TV005 is a National Institute of Allergy and Infectious Diseases and Butantan Institute vaccine using wild type strains with genetic mutations engineered to reduce virulence. Results from phase III trials are due late 2018 (Normille, 2017).

### **Reproductive Ethics**

The highest case rate of microcephaly with 4,300 cases dating from 2015 was reported from Brazil where health care resources are limited and in a particularly impoverished region. Care of a microcephalic child poses a dilemma for mothers with other children. Responding to the crises, the Brazilian Ministry of Health published guidelines with recommendations regarding family planning. In Brazil, abortion is illegal. The Zika emergency illuminates inequities in the healthcare system and lack of reproductive health services along with restrictive abortion laws (Dinz et al., 2018).

Latin America accounts for 40% of the world’s population of Roman Catholics and as of 2014, 69% of Latin Americans identify themselves as Catholic. The Magisterium (teaching authority of the Roman Catholic denomination) opposes contraception and abortion which in turn has influenced the policies of the regional governments. Recommendations vary across countries, some recommending women postpone pregnancy for 6-12 months during the outbreak. In order to reduce spread of the ZIKV and prevent more cases of microcephaly. Abstinence policies are not overtly negative, but they are not easy to follow either without realistic and practical support. One undergraduate observed: “Latin American countries have given women a recommendation without providing resources for them to fulfill it.”

Family planning services including contraception and sex education are highly effective ways for women to control their bodies but services are not wide spread or easily accessible. Contraception can include products other than condoms, such as intrauterine devices which in some cases prevent pregnancy. One such device was added to the World Health Organization Essential Medicines List in 2015 but only Chile among fifteen countries in Latin America provided the device to the

public (Ali et al., 2017; Jamrozik and Selgelid, 2017). Women resort to unsafe abortions to avoid unwanted pregnancies or high-risk pregnancies especially in nations with vigorously enforced criminal abortion law. In the face of a public health emergency, governments struggle to balance public health interests such as compulsory containment, contact tracing, and mandatory reporting against personal autonomy and privacy.

Under the International Covenant on Economic, Social and Cultural Rights, the Committee on Economic, Social and Cultural Rights addresses the issue: “the right to sexual and reproductive health entails a set of freedoms and entitlements.” The freedoms include the right to make free and responsible decisions and choices, free of violence, coercion and discrimination, over matters concerning one’s body, sexual and reproductive health. The entitlements include unhindered access to a whole range of health facilities, services and information, which ensure all people full enjoyment of the right to sexual and reproductive health under article 12 of the Covenant” (Diniz et al., 2016).

In principle, reproductive health rights should apply to the control of and promotion of reproduction. Brazilian law does not bar a woman’s use of contraception, but it also does not provide all women access to it. It is ironic that the Ministry of Health would direct women to avoid becoming pregnant during the height of the Zika outbreak without providing access to contraceptives. To punish any attempt to terminate affected pregnancies is callous. In the words of Dinez et al. (2016): “Politicians’ indifference to, if not sympathy with religious opposition to, lawful, safe abortion is liable to remain while they and their families are unaffected. Disadvantaged women with low incomes have to face hazardous pregnancies and legal constraints on termination, whereas, ‘middle- and upper-class’ women, who have the means to seek a private clinic, can count on a wide net of abortion and post-abortion services – clandestine in many cases but also a few that are somewhat more mainstream – usually undisturbed by the legal prohibition or enforcement agencies...This disparity is a key element in keeping the widespread opposition to abortion intact, since a change in the legislation is much less important for the most politically and economically influential segments of society given that they do, to a large extent, get the appropriate abortion services they need...and avoid any negative consequences to their social, moral and religious standing.” Class discussion raised the point that whereas less restrictive abortion laws would ease the burden on some women, it would be preferable to have equal access to reproductive planning services at all times.

Recommendations that women avoid or delay pregnancy, practice safe sex or abstain from sex during pregnancy all assume that women in affected regions enjoy high levels of reproductive freedom and self-determination. Restrictive abortion laws in many countries in Latin America leave women who may wish to discontinue their pregnancies with little access to safe, legal termination and leave them exposed to the risks of unsafe procedures. The International Planned Parenthood Federation: “poor women and adolescents living in rural areas, where mosquitoes are a part of

everyday life, are more susceptible to infection and less likely to have access to sexuality education, contraception, and safe abortion services where legal. In Brazil, for example the epidemic is concentrated among young women of color living in the least developed areas of the country” (Davies and Bennett, 2016). Zika represents ethical issues of long-standing concern in bioethics such as those related to prenatal testing for fetal malformations and global disparities in health outcomes.

### Children's rights

Brazil ratified the Convention on the Rights of the Child (CRC) and the Convention on the Rights of Persons with Disabilities (CRPD). Consequently Brazil has promised to provide assistance “free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child’s achieving the fullest possible social integration and individual development” (Diniz et al., 2016; Brasil et al., 2017).

### Zika vaccine ethics

The most efficient and cost effective prevention of a virus is a vaccine. Eradication of smallpox is the proof of what an effective vaccine can do. Contemporary creation of vaccines employ biotechnology and recombinant DNA techniques. The ideal vaccine mimics a normal infection, triggering antibody that can neutralize the virus (block its attachment to a new host cell) and cell-mediated immune clearance of virus infected cells. Full protection requires both arms of the immune response in order to be fully protective. Any vaccine offered in a new pandemic such as Zika would be experimental. Thus the ethical question is what kind of testing for a Zika vaccine is reasonable and ethical?

Should women who are pregnant and at risk of infection be given special consideration for vaccination or should be get other preventative help such as mosquito control? Is it exploitative to take an unproven vaccine into a community suffering high infection rates? What is the risk-benefit ratio and how does one calculate it when the vaccine is not yet proven protective?

To avoid charges of exploitation, an alternative to determining the merits of an experimental vaccine is a challenge study. Herein, the vaccinated subjects would be given a (challenge) infectious dose of Zika. Placebo controls would become infected whereas the vaccinated persons “should” resist infection. This approach would rely on fully autonomous individuals volunteering with fully informed consent in a place not in the midst of an outbreak.

Shah, S.K. et al. (2017), released a report and set of recommendations on the “Ethical considerations for Zika virus human challenge trials.” In the executive summary the authors answer the questions: Can a Zika virus human challenge trial be ethically justified? If so, under what conditions? “Given the potentially devastating effects of Zika infection during pregnancy, the insidious nature of the disease, and the promise of what can be

learned from human challenge trials, the writing committee, concluded that a Zika virus human challenge trial could be ethically justified if certain conditions were met. However, at this point in time, based on what was heard at the consultation meeting and on our review of the latest scientific and ethics research, the writing committee has determined that these conditions preclude the conduct of a Zika virus human challenge trial, as detailed in the body of the report.” (Shah et al., 2017). Conducting such a study should recognize a clear potential for public health impact and there should not be alternative means to gather the same information. The study should collect and produce reliable, relevant data. The committee did not recommend challenge trials based on social benefit analysis that considered the following questions: Are vulnerable populations protected? Is there a robust informed consent process? Is the level of compensation adequate but not undue? Is the right to withdraw respected? Have independent expert reviews been conducted? Is there a system of compensation for injury? Is there a plan for community engagement?

Students debated the ethical justification for a challenge study vs. experimental vaccine trials in the midst of an outbreak. Issues discussed were compensation risk being coercive; recruiting homeless people or those in need of health care, as vulnerable population more likely to be exploited in the name of scientific research. Much concern was raised over whether pregnant women should be included in the vaccine. Given the disappointing results of the first released Dengue vaccine and reports of cross reactivity between Dengue and Zika, the place and population becomes even more sensitive an issue (Blackman et al., 2018). Current epidemiology of Zika is still emerging (Bamberg et al., 2016). Alternatively, a field trial among at-risk individuals raises questions too. The number of Zika cases has dropped so sharply that it may be difficult to do field trials. If a virus is not spreading, the protectiveness/effectiveness of the vaccine cannot be measured (Cohen 2017).

### Vector Control

Alternative to vaccine, protection of people against *Aedes* mosquitoes could provide a solution that protects against all the viruses borne by this vector. It is a key public health recommendation for mosquito borne viral diseases. Insecticide use has led to resistance in *Aedes* mosquitoes. New technologies such as *Walachia* infected mosquitoes designed to interfere with reproduction may be ecologically safer than genetically modified mosquitoes, a conjecture without supporting scientific data. (Resnik, 2014).

### Summary

Zika as a case study illustrates how profoundly injustices in resource distribution and healthcare anywhere in the world is a threat to everyone in the world. It is clear that the hardest hit communities lack access to basic preventive measures such as mosquito nets, contraception, maternal health services. Global attention to the plight of the underprivileged reveal how local epidemics become pandemics through population movement, urbanization, deforestation, and climate

change. Sadly those most at risk to climate change disease burdens are those who contributed least to carbon emissions (Jamrozik and Selgelid 2017). Outbreaks of Zika illustrate the interconnectedness of humanity in a world of airplanes and social media. People within an outbreak depend upon WHO and international help for fast and accurate communication of new hotspots of infectious diseases. Public Health services are charged with a rapid response to a crisis, educating the public to reduce stigmatization of victims and curtailing transmission of the virus. As disease outbreaks challenge public health resources and international collaboration, they provide interesting, timely and relevant material for ethics education.

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## Global Challenges in Sustainable Public Health

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### Introduction

Sustainable development requires practices and policies that protect human rights and simultaneously encourages development of human flourishing, within an ecosystem that is vibrant and healthy. It is counter-intuitive to suggest that the animals and plants and humans cohabitating on planet Earth are indestructible or merely exists for the benefit of humans. The goal of sustainable development is: “*healthy people living on a habitable planet*” (Sachs, 2015 p1). Societies are diverse in many aspects and universal in others. A virus that spreads through a mosquito bite is immune to social diversity: nature instructs them to feed and replicate and human infections are no more than bystander effects. Emerging viruses such as Ebola reflect the delicate web of interactions between the ecosystem and humans. Distribution of technology to diagnose, treat and prevent diseases invite a stronger health care capacity. This paper will explore and contrast theoretical and actual responses to virus outbreaks, using the recent outbreak of Ebola in western Africa as a case study. Sustainable development requires a safety net finely woven with threads from economy, society, environment and politics. Justice is the fair and equal treatment of human beings according to their needs. Using a social contract



framework of justice embraces human rights and sustainable development.

### Human Rights

Human Rights posits that every person, regardless of their relative social position is inherently due the conditions necessary for wellness (Sachs, 2015 p 226). Inherent in the Universal Declaration of Human Rights (UDHR) is the notion that every human being derives rights simply by being human. Whether the document continues to be universal can be tested in the reality of infectious diseases that spread by vector or human mobility. What humans need to sustain health and wellbeing is less controversial than who has the duty or responsibility to provide reasonable availability of resources needed to claim that right.

Psychologically, humans require social interaction, relationships, and a sense of community. Physiologically, humans need food, water, shelter and health care. The concept of human rights recognizes the psychological and physiological dimensions. At the basic survival level, meeting physical needs takes time, attention, and energy with little left over for more liminal goals. In contrast, if a person lives in a place where the basic necessities are assured and does not need to struggle to survive, time and effort can shift to developing new technologies, improving community solidarity, and contributing to sustainable development.

UDHR grants all persons the right to health care (Article 25). Sadly, individuals, nations, and institutions may make choices that ignore or violate human rights without evident consequences. It takes a vigilant neighborhood watch approach to expose injustices. A coordinated approach has more impact but it takes committed individuals and responsive governments to provide universal access to health care or any other system that provides an opportunity to claim one or more human rights.

Failure to secure basic human rights for every member of the human family only exacerbates existing inequalities, widening the socioeconomic disparities between individuals creating what Paul Farmer calls the "poverty trap". No right can be a human right unless it is an equal right (Khatchodourian, 1985 p. 231). Human rights invite active listening to those whose experiences require empathy and responsiveness. What we understand about the plight of another may well inform the choices we make on a daily basis. One example is the way we measure development in terms countries Gross Domestic Product (GDP). Certainly measurement of GDP fails to consider other conditions that can affect human wellbeing. Many countries increase GDP by maximizing energy and resource 'throughput' without a future vision of sustainability (Beddoe, 2009).

### Sustainable Development Goals

The Sustainable Development Goals (SDG) were adopted at the 70<sup>th</sup> Session of the United Nations in 2015. The 17 goals endorsed by Heads of State and Government Leaders represent a universal, ambitious, sustainable development agenda. In Table 1, the 17 goals are listed with the principle objective and rated for relationship to public health directly or indirectly. A directly related goal such as extreme poverty affects the

ability of a person to obtain sufficient food, shelter, clean water all of which reduces well-being and health. Quality education indirectly affects health when a person lacks a clear understanding of how an infectious disease is transmitted and what can be done to prevent it. Ten of the seventeen goals directly affecting public health especially outbreaks of infectious diseases such as Ebola.

It can be difficult to impress citizens of the world or of any one nation with the reality that all epidemics are not infectious diseases. The obesity epidemic is an example. In many parts of the world overeating is more of a problem than famine. In rich communities' residents eat salad, while the poor neighbor miles away push away hunger with a hamburger or pizza. In 2014 more than 2.1 billion people were overweight, compared to 850 million who suffered malnutrition. In 2010 famine and malnutrition killed about one million persons whereas obesity killed 3 million (Mokdad, et al. 2016).

Table 1: Sustainable Development Goals and their relationship to health

GOAL #	GOAL OBJECTIVE	Related to public health (yes-directly or indirectly)
Goal 1	End Poverty	Yes directly
Goal 2	End Hunger	Yes directly
Goal 3	Well-Being	Yes directly
Goal 4	Quality Education	Yes indirectly
Goal 5	Gender Equality	Yes directly
Goal 6	Water and Sanitation for all	Yes directly
Goal 7	Affordable and Sustainable Energy	Yes directly
Goal 8	Decent Work for all	Yes indirectly
Goal 9	Technology to Benefit all	Yes directly
Goal 10	Reduce Inequality	Yes directly
Goal 11	Safe Cities and Communities	Yes indirectly
Goal 12	Responsible Consumption by all	Yes indirectly
Goal 13	Stop Climate Change	Yes directly
Goal 14	Protect the Ocean	Yes indirectly
Goal 15	Take Care of the Earth	Yes indirectly
Goal 16	Live in Peace	Yes directly
Goal 17	Mechanisms and partnerships to Reach Goals	Yes directly

### Ebola outbreak in Western Africa

Historically infectious diseases were second only to hunger as a threat to human life and longevity. With the advancement of science, development of vaccines, antibiotics and antiviral drugs, the plagues of history seem gone for good...until...another Ebola outbreak occurred in 2013 in three nations of West Africa that had never had a case of Ebola. This outbreak infected 28,000 people and 11,000 died. By early 2015, the epidemic was controlled by good public health initiatives: testing, isolation, contact tracing, and education. The WHO

declared it over in January 2016. It was a reminder that epidemics still occur, but public reaction was critical of WHO for not containing the outbreak faster. The false assumption is that humans have the knowledge and technology to prevent or curtail plagues whenever and wherever they occur.

One lesson learned from the Ebola outbreak in West Africa is the importance of health care infrastructure and trained health care workers. Good health is at the center of human well-being, a precondition for a person to be a functional member of society (Sachs 2015, p275). Anyone can be sick and unable to work. If a person lives in poverty, the web of influence spreads: loss of wages means lack of money to buy food, or pay for medical care if it is even available. Being unable to afford medical treatment, the person may recover more slowly and if their disease is infectious in nature, they infect others.

### **Universal Access to Treatment**

In the Ebola outbreak, lack of universal treatment lead to increased rates of transmission. Treatment (standard of care) for Ebola includes maintaining fluids, reducing fever, and providing supportive care. If received, standard of care can reduce the mortality rate by half. Prompt and accurate diagnosis is a challenge if the disease appears in a new region as it was in West Africa. Providing health care workers with proper personal protective equipment (PPE) helps protect them from infection and allows them to work for the benefit of all who are sick. Ebola spreads from person to person, through exposure to bodily fluids. Funerary customs and close living quarters increase probability of viral transmission (Luge, 2015).

Reports of people going into a home to deliver food unaware that a person inside was infected, or a symptomatic person refusing to go to a hospital, increased fear of the disease and stigma for those infected. The idea that people could be exposed to a virus with a 50% mortality rate, increased the focus on Ebola Education. One of the keys to controlling the outbreak is in the form of better public education programs. It may be necessary to recruit local representatives for educating the public to get the best results.

Bubonic plague in the 14th century established good practices for limiting spread of an infectious agent consisting of a quarantine zone and prohibition people entering and leaving the zone until the outbreak was over. To get supplies to the quarantine zone, help was essential for food, water, medicines, equipment. Within the zone, healthcare workers face a high risk of infection, as they are in direct contact with symptomatic patients. If the healthcare workers are contained within the zone, it affects their families, and may result in a limited capacity to care for the sick.

Increased air and sea travel changes the notion of borders. Small to extreme differentials in transnational inequality are exposed and play an important role in emergent disease transmission dynamics. Comparing the outbreak in West Africa in 2013 with the most recent outbreak in Congo illustrates several important lessons. In Guinea, Sierra Leone and Liberia, infected individuals would opt to stay home and be cared for by a family member, or to travel to a medical facility in a nearby city. The exposure of the household members and their

contacts spread the virus in widening concentric circles, but the introduction of the virus into a city hospital has the potential to send virus in radial arcs beyond the city.

The Democratic Republic of the Congo (DRC) has dealt with seven Ebola outbreaks and is currently dealing with the eighth. The health care workers and Ministry of Health are well coordinated in dealing with the virus. Two lab confirmed cases and 48 probably cases had 350 contacts, all of which were monitored. The location where the outbreak occurred had few roads and bridges necessitating supplies be delivered by helicopters. Mobile labs were established, for testing and treatment and containment. Quick, proper isolation of patients, contact tracing and quarantine has worked in the past and should limit this epidemic as well – unless one infected person reaches a large city (Cohen, 2017).

### **Health Care System**

WHO defines a health system as “built on having trained and motivated health workers, a well maintained infrastructure, and a reliable supply of medicines and technologies, backed by adequate funding, strong health plans and evidence based policies?” (WHO. Health systems: World Health Organization <http://www.who.int/healthsystems/about/en>). The unprecedented spread of Ebola has been explained in many ways, such as human mobility between affected countries, cultural practices like traditional burials and inefficient health system. Each of these three countries have had civil wars with a negative impact on health system infrastructure. In Guinea, health workforce density is less than 1.5 per 10,000 population with three hospital beds per 10,000 people. Per capita government expenditure on health is 9 US\$ per year. Sierra Leone has a workforce for health care of 2.2/10,000, 4 beds per 10,000 in hospitals, and equivalent expenditure, 12 US\$ per year. Liberia has less than 3.7 health workers per 10,000, about 8 hospital beds per 10,000 and per capita expenditure on health of 13 US\$ per year. All three countries noted lack of medical supplies, transport systems and diagnostic tools. It is important to surveillance and isolation to have accurate and available diagnostic tests. The outbreak is an educational case study in public health, with lessons about how to build resilient health systems, and invest in capacity building (Shoman et al., 2017).

Between 1 January 2014 and 31 March 2015, 815 cases (confirmed and considered probable) occurred among health workers in the region (328 in Sierra Leone, 288 in Liberia and 199 in Guinea). An additional 225 suspected cases were reported but were not part of the analysis. Nurses, Nurse Assistants and Nurse Aides account for 50% of infections, and 77% of them were hospitalized. However, the case-fatality ratio was not statistically significantly lower than among non-healthcare workers infected. Among health workers 39% were female and 61% male. In contrast among non-health workers 52% were female and 48% male. “It is difficult to establish the setting where health workers acquired the infection. They may have occurred in health facilities where triage may have not been effective and health workers unknowingly provided care to Ebola infected patients. It is also possible that the infection was acquired in the community with or without linkage to

care provision" (WHO Preliminary Report, 2015). The report lists a number of recommendations for future use, including better point of care assessment and differential diagnosis, better supplies and training, isolation of Ebola patients from general patient wards, safe transport vehicles, environmental controls, such as hygiene stations, alcohol and chlorine based disinfectants, disposal system, adequate PPE. Certainly healthcare workers have rights to protection in an outbreak with a mortality rate as high as Ebola's. Governments need to institutionalize policies to protect healthcare workers in order to offer effective care and increase confidence in health system (Yakubu, et al., 2014).

Ebola is one of several "emerging" viral diseases. Gaining visibility in press coverage has helped to give a sense of urgency and to leverage funding for research. It is difficult to limit an explanation to one discipline, even though virologists will claim expertise in the pathogenic mechanism of the illness, and immunologists and vaccinologists will search for treatment and prevention measures, emerging diseases are more complex than their biology. "Responsible factors include ecological changes, such as those due to agricultural or economic development or to anomalies in the climate; human demographic changes and behavior; travel and commerce; technology and industry; microbial adaptation and change; and breakdown in public health measures" (Farmer, 2010).

Certainly the fragile health system affected the length and penetrance of the outbreak. Limited numbers of clinics for diagnosis and treatment, fear or lack of understanding about transmission of the virus, and limited resources in terms of health care workers and facilities means everyone will not receive standard of care. This is the harsh reality of the conditions when the Ebola outbreak spread across Guinea, Liberia and Sierra Leone. This outbreak demonstrated a real crisis and exposed the lack of sustainable health care staff and resources needed for an effective response (Gostin et al., 2014; Boozary et al., 2014).

#### **Diagnosis: fast and accurate**

Ebola outbreaks prior to 2013 were mainly in equatorial regions such as Congo. Familiarity with the symptoms and being alert to the infection through experience means that an outbreak in Congo is more likely to be recognized sooner than a few cases in Guinea where until 2013, there had never been a case. Not expecting Ebola, but having other hemorrhagic fever virus infections such as Lassa Fever requires a differential test that is quick and accurate. Different testing strategies were used in this case. For example, in Guinea deceased individuals were not tested for Ebola meaning these persons were not counted as confirmed cases, unlike in Liberia and Sierra Leone. Use of a consistent protocol, case definition, will improve data collection and analysis. Modern molecular techniques such as Reverse Transcription -Polymerase Chain Reaction (RT-PCR) is sensitive, accurate, and differential, but it requires the equipment, electricity, technicians to run the assay. The method is available in the major city hospitals in Liberia, Guinea and Sierra Leone, but samples of blood have to be taken, labeled, and transported and the results communicated. It may not

yet be practical to expect comprehensive coverage of very rural societies. More effort should be made to develop rapid spot tests even though less sensitive for preliminary diagnosis, so that the alarm to trigger public health interventions can curtail the spread of the virus. Collecting and analyzing data from an epidemic is essential to standardizing responses and learning the most efficient and effective interventions (Cori et al., 2017).

#### **Human Right to Health Care**

Human rights provide an ethical foundation for why and how remote areas of the world ought to have assistance in building a health care system to promote and protect human health. National Human Rights Institutions help societies and individuals move toward sustainability, ensure accountability to governments who have a duty to create conditions wherein citizens can claim their rights. These same organizations in concert with government in nation-states can protect human rights from exploitative systems (Jensen, et al., 2015). After citing this report, one undergraduate observed: "In our endeavors to exercise the rights we have been granted, we must take care so as not to infringe upon the rights of other human beings. Each of us is born into conditions that we cannot control. Where and when we were born, and the resources that our parents had factor into shaping our lives. ...What matters just as much as the resources humans need to live a life of health and dignity are the ways in which we utilize the resources we have been given as we attempt to address the problems at hand."

Medicine and allied health sciences are marginally involved in human rights advocacy. Fifty years ago, with the crafting of the UDHR, Article 25 addressed health within the broader social and economic rights: "Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control." The exclusive use of the male pronoun testifies to the age of the document. However, it is sad to admit that so little progress has been made. Paul Farmer rightly observes: "An irony of this global era is that while public health as increasingly sacrificed equity for efficiency, the poor have become well informed enough to reject separate standards of care." (Farmer 2010).

It is humbling to include Human Rights in courses taught in the United States at this time of political tension and policies that are contrary to the broad scope of rights proscribed in the UDHR. Years ago Michael Ignatieff warned in Human Rights as Politics and Idolatry, that hypocrisy too often is exposed in the actions nations take. "Human rights is increasingly seen as the language of moral imperialism just as ruthless and just as self-deceived as the colonial hubris of yesteryear" (Ignatieff, 2001, p19).

Human Rights should be recognized as universal, but unity is not uniformity. Human Rights advocates bear the burden of systemic misuse and hypocrisy, such as happens when a nation violates civil or economic rights

within and points to human rights infringements within another country. Sadly, my own country is guilty of this and it is very difficult for students to recognize it. All forms of suffering are not equivalent. Some harms encompass subpopulations whereas others differentiate on more personal criteria such as the ability to pay for health care.

As science progresses in development of new diagnostic tests and treatment protocols, our human capacity to distribute them equitably lags. The poor, the vulnerable, women and children, migrants and illegal aliens constitute a huge control group of the untreated. Farmer is right in noting that “the withdrawal of states from basic business of providing housing, education, and medical services usually means further erosion of the social and economic rights of the poor.” (Farmer, 2010).

Perhaps it is time to recognize that consensus on human rights may find plurality in practical policies that befit cultural differences. Charles Taylor suggests that international consensus on human rights can accommodate a diverse set of values on norms of behavior without rejecting what humans have in common (Taylor, 1999). It is not necessary to prioritize the human species over all other life forms to embrace rights. It only requires recognition of the fragility of the human person whereby the capabilities individual persons need to function and live a life of dignity. Nussbaum lists life, bodily health, bodily integrity, sense cognition, emotions, practical reason, and affiliation in families, communities, play, awareness and relationship with world of nature, and control or influence over one’s environment (Nusbaum, 2011). The requirements for human flourishing are the subject of the rights claims.

Correspondingly, the duty to provide conditions wherein the holder of rights can make just claim is the nation state. Students insist that human rights are recognized as an ideal: that the realization of them is lost in political chaos. They are cynical before they reach the end of the second decade of life that what seems obvious is so difficult to achieve. They quote Rawls, “Original position and veil of ignorance” over and over, from freshmen to seniors, they say, “If we could only see that the poor person begging for food, trying to reach a safe place to raise their children, acquire health care could be me, we might act differently” (Rawls, 1971).

### **Ebola outbreak as case study**

The Ebola outbreak is an excellent case study of how interconnected people are in this world. The first case in Guinea was December 2013 and within a year cases were reported in Liberia, Sierra Leone, Senegal, Nigeria, Spain and the USA. It is clear Ebola is a threat to public health for the global community. The principles and individualistic focus of medical ethics fails to prioritize global injustice and that was all too clear in the recent outbreak. Experimental vaccines and monoclonal antibody therapy in very limited supply were sent for testing with no doubt an intent to help, yet none of the products were known to be safe or licensed for human use.

It is worth ethical reflection on whether in the midst of a public health crisis, an experimental vaccine can be adequately tested. Would not anyone infected with a virus with a 50% chance of death be willing to accept an

unknown risk from an unlicensed preventive vaccine? WHO committee reviewed the use of the vaccine and set criteria that reflect the usual concerns about informed consent, freedom of choice, confidentiality, respect for the person, preservation of dignity, involvement of community (Dawson, 2015). Several of the expressed criteria are generally considered part of an informed consent process, even involvement of community in some cultural circumstances. Additional considerations were given to transparency, trust, fair distribution in the face of scarcity which reflect the Helsinki guiding principles. The committee concluded that it was good and right to test experimental vaccines and treatments in the best possible clinical trials under the circumstances in order to prove or disprove their utility. What they did not do was call upon nations to join in responding to a public health crisis of unprecedented scope (WHO 2014).

Students discussed the situation and how dire conditions seemed to be for the basic coverage of health care to those who were sick and protection of those not infected. They could not imagine how a clinical trial could be done in the middle of the epidemic without either distracting from the primary care of patients, or risking a charge of exploitation. The priority for a robust public health effort to contain and combat the disease would show the most solidarity with those living in the affected region. Neglect of the public health infrastructure is an example of global injustice that should be addressed long ago and that is very apparent in the Ebola epidemic.

### **Conclusions**

To see in the other a reflection of myself is a way of being in a diverse and complicated world. The real and equal value of human beings brings moral weight to human rights, especially in the context of a deadly viral outbreak. The International Bill of Human Rights does not base the common needs of human beings on a creed or religious text, a particular strain of philosophical or sociological or political thought, rather, it articulates the experiential lessons learned from watching what happens when we fail to treat humans humanly (Boyd, 2014). The Ebola outbreak highlights the need for universal health care infrastructure as a global justice priority. Testing vaccines and passive immunization with antibody can be a straight forward way to determine efficacy, but in the midst of the chaos of a medical emergency, it raises questions unanswered as yet. It was clear that foreign workers who became infected were medically transported to home hospitals and not treated in country. Does this not demonstrate in a global era, the need for policy goals that resist a double standard for the rich world and the poor world? We need a shift from what went amiss in respecting and protecting human rights in the context of public health to what we should do. We need an agenda for action that builds trust and solidarity within and among nations.

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## **Book Review of: International Biolaw and Shared Ethical Principles: Universal Declaration on Bioethics and Human Rights,**

Edited by Cinzia Caporale and Ilja Richard Pavone, Routledge Taylor & Francis: Abingdon and New York, 2018. 164pp. ISBN 978-1-315-58931-2 (ebk). ISBN 978-1-472-48398-0 (hbk)

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This volume is a collection of ten essays that reflect upon the significance of UNESCO's role in further widening human rights, the efficacy and strength of the Universal Declaration on Bioethics and Human Rights (UDBHR) non-binding soft law that was adopted by 191 countries in October 2005. The UDBHR formed a third pillar, along with the Universal Declaration on the Human Genome and Human Rights of 1997 and the International Declaration on Human Genetic Data of 2003, to establish bioethics within internationally agreed soft law. In an early chapter Roberto Andorno reminds readers of the roots of UNESCO's role in establishing global human rights being from the horrific events of the Second World War and the resulting Nuremberg Code. The UDBHR went further than previous legislation as it broadened bioethics beyond biomedical related ethics to include in Article 17 recognition of the environment and biodiversity as being integral. The aim of the UDBHR was to provide a framework of principles and procedures as a guide for states to formulate legislation and policies in the field of bioethics. Collectively this text provides illustrations of how far progress has been made towards this goal.

Part II of the book specifically deals with the UDBHR contribution to globally shared bioethics. The UDBHR has illuminated ethical concepts such as dignity, informed consent and relevant environmental issues such as overpopulation, poverty and pollution. Article 23 of the UDBHR states the requirement for meaningful bioethics educational programmes. The development of the Core Curriculum Syllabus for the teaching of Bioethics was published in 2008. Two authors in this text applaud the content within this curriculum but do not go as far as to include discussion of how this been included within the statutory curricula of different states or

higher education establishments let alone any evaluation of case studies that illustrate the impact of this bioethics curriculum on changing the attitudes, behaviour or cognitive abilities of the students who have followed the programme.

Pavone recognises some issues such as the legal status of human embryos or gene therapy that were not specifically addressed within the UDBHR and the limited new bioethical principles that were introduced at that stage. However, the unanimous acceptance of the declaration without any objections was a significant achievement and gives the UDBHR more weight than similar recommendations of international NGOs. Furthermore, it may have a level of compliance equivalent to, or greater than, hard law treaties such as the 1992 UN Framework Convention on Climate Change or Paris Accord of 2015.

In one essay Thomas Faunce argues the role of bioethics to assist in the transition from the “corporatocene” where multinational corporations could challenge nation states’ legislation (as tobacco giants have done in Australia for example) to the “sustainocene” where global pathologies will be effectively addressed such as climate change, environmental degradation or societal imbalances in access to food, fuel and medicine to name a few. Encouragingly he identifies artificial photosynthesis as being an ethical and potentially viable solution to many of these ills, and proceeds to justify the case for the next UNESCO soft law to be a Universal Declaration on Photosynthesis and Human Rights. Surely that would bring a ray of sunshine to the global outlook:

A limitation of this volume is that few contributors are from outside Europe; none are from Asia, South America or Africa. Thus in some discussions an unawareness of great work that has been accomplished is revealed. For example Emilia D’Antuono and Emilia Tagliatela make no reference to UNESCO Bangkok’s Asian-Arab Philosophical Dialogue publications when they attempt to seek a definition of dignity. Similarly, there is a void in this collection that should have shared and credited the work of UNESCO’s own Ethics and Climate Change in Asia and the Pacific (ECCAP) working groups in the reports such *Water Ethics and Water Resource Management*, *Ethics and Biodiversity*, *Energy Equity and Environmental Security*, *Energy Flow, Environment and Ethical Implications for Meat Production* or *Asia Pacific Perspectives on Bioethics Education* all of which explore real applications of the UDBHR in depth. This void is apparent as *International Biolaw and Shared Ethical Principles* has devoted more emphasis on the biomedical principles and ethical issues rather than those addressed in Articles of the UDBHR that concern bioethics education, the environment and biodiversity and future generations. Consideration of the applauded ECCAP reports for example would have provided a more global insight into the legal, application and adherence to this *universal* agreement.

Collectively this volume provides a good background to the history of the development of the UDBHR from a Eurocentric or Western perspective. The momentous

task of uniting nearly 200 nations into a formative agreement on standards must not be underestimated. Hopefully future researchers will adhere to these principles and standards as the routine minimum and therefore this is a useful text for many undergraduate and graduate students. For all those working in the field of bioethics it will also be a welcome addition to their library as it welds together several themes.

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