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## **Editorial: COVID19 and Health**

Although we are at the beginning of the new decade, and the new year 2020, already we can predict that the dominant health issue of the year is the emergence of a novel coronavirus, named COVID-19. Although this started in Wuhan, China, the net around the city was closed too late and the virus has spread globally. Each country attempts to limit the spread of the virus through a variety of measures, and quarantine and social distancing have led to dramatic impacts of the global economy and on the ethics of people as they panic. Please be calm!

American University of Sovereign Nations (AUSN) has just launched a new Postgraduate Certificate Program to prepare people and communities to respond to COVID-19.: [https://ausn.info/postgraduate\\_certificate\\_in\\_epidemics\\_and\\_ethical\\_global\\_health](https://ausn.info/postgraduate_certificate_in_epidemics_and_ethical_global_health)

One of the most significant trends of the past decade has been the increasing accessibility to international travel, where many persons see the world as a place without borders. Medical tourism is discussed by Ann Boyd et al., in this inaugural issue of 2020. Ironically, with the travel restrictions imposed by many governments as a response to COVID19, a pandemic disease, medical tourism is being affected negatively. Still humanitarian exceptions are permitted by most countries.

The next two papers in this issue look at cases of how culture affects treatment, with Hayashi and Miyasaka documenting a husband's experiences of a Japanese couple following fertilization with a donated egg. Mukhamedzhanovna and Akmalovna describe Islamic philosophical, religious and ethical traditions in medicine in Uzbekistan.

An ethical proposal for Universalism versus relativism in research is proposed by Al O. Giwa. A Malaysian study with broader generalizability on fostering integrity in scientific research: understanding conflict of interests (COI) through responsible conduct of research, is presented by Olesen et al. We welcome further papers to explore cross cultural bioethics.

- Darryl Macer

## Patients without borders: medical tourism

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### Abstract

Medical tourism is a form of medical travel wherein patients move across borders from their home country to another for the purpose of seeking medical treatment that is unavailable or unaffordable at home, for the privacy of a transnational location, or for the tourist destination attractions. Medical tourist may seek procedures not approved at home, such as stem cell treatments, or physician assisted suicide. International travel for procedures legal at home and in the destination country are predominately motivated by affordability and shorter wait-time. In the U.S. some insurance agencies offer reimbursement if a patient goes abroad and has a procedure that is drastically cheaper. Globalization of health care is becoming a fact of life and medical tourism is only one facet of the picture. This paper will examine what we know about medical tourism from a literature survey and evaluate ethical concerns including welfare of patients (quality of care, patient safety, communication), impact on healthcare systems in destination countries, and effect of medical travel on public health.

### Introduction

Medical tourism is a form of travel wherein patients move across borders from their home country to another to seek medical treatment that is unavailable or unaffordable at home, or for the privacy of a transnational location or the tourist destination attractions. However, medical tourists may seek procedures not approved at home, such as stem cell treatments or physician assisted suicide. International travel for procedures legal at home and in the destination are predominately motivated by affordability and shorter wait-time. In the USA, some insurance agencies offer reimbursement if a patient goes abroad and has a procedure that is drastically cheaper. Globalization of healthcare is becoming a fact of life and medical tourism is only one facet of the picture. This paper reviews medical tourism through a literature survey and evaluates ethical concerns including welfare of patients (quality of care, patient safety, communication), impact on healthcare systems in destination countries, and the effect of medical travel on public health.

### How do people in the US decide to use a foreign provider for a medical procedure?

Do they investigate the international financial complexity or the impact of healthcare investments in the destination countries on the poor? It is likely

that persons facing a healthcare need and difficulties to have it performed at home, regardless of the country in which they live, may in the age of Internet simply investigate possibilities to obtain the treatment they need. Some private hospitals advertise internationally their high-tech procedures, Western-trained physicians and comfortable accommodations.

### Motivation for medical tourism

Patients paying out of pocket for elective medical procedures can shop through websites of hospitals and medical tourism companies for the procedure they want. Some medical tourism companies also offer to make the needed arrangements. including travel, visa application, hotel accommodation, and holiday excursion. Patients choose from among healthcare packages and travel to their selected destination. Whereas the term "medical travel" indicates the only purpose is the treatment, "medical tourism" may imply other factors, such as more comfort and privacy.

As of 2013, 47 million Americans lacked full health insurance: some are uninsured, others underinsured. For these individuals, the dilemma is whether to go into debt to have a medical procedure in the US, travel to obtain care at a more affordable price, or go without the medical care they need (Turner, 2013). Lacking a systematic comprehensive global database to document how many patients leave home to receive care at international sites, it is difficult to know who is traveling where and why.

Hanefeld (2014) analyzed 100 publications for patterns motivating medical travel and medical tourism. Destination countries are known for special types of medical care. Thailand is known for cardiac, orthopedic and gender reassignment surgery. Singapore specializes in high-end procedures such as stem cell therapies. Spain is favored for fertility treatment and Eastern Europe for dental work. Motivation includes cost savings, waiting time for a procedure, and availability. Travelers seeking more cosmetic elective procedures cite privacy, comfort with type of care, and cost.

In a 2016 report released by VISA and Oxford Economics, the medical tourism industry was valued at US \$439 billion with a projected growth rate of up to 25% year-to-year for the next decade. The Medical Tourism Index (MTI) lists 41 destinations for those seeking value-added services and high-quality healthcare (<http://www.medicaltourismassociation.com>, accessed 6/23/18).

### Cost savings case

Howard Staab, a 53 year old resident of the US needed heart surgery to replace a failing mitral valve but he had no health insurance. The local hospital cost of the surgery was \$200,000 with \$50,000 down payment and arranged payments after surgery for the remainder of the bill. His wife began to search for alternatives. A sympathetic Texas doctor offered to do the procedure for \$45,000. The couple turned to

the internet for alternatives. The valve replacement was performed at Escorts Heart Institute and Research Center in New Delhi. Treating a postoperative complication with a second operation, and remaining in India for a month for the total rehabilitation, the couple paid \$10,000 including air fare (Turner, 2007). The \$190,000 differential between local US hospital-based valve replacement and the procedure in India helps explain why some uninsured and underinsured US citizens are willing to travel to access affordable care.

### Medical brokerages

Medical brokerages promote travel, cost-effective healthcare, quality care, and good accommodations. The companies showcase comparative prices between countries for the same procedure. Singapore, Thailand, Mexico and India are ten-times cheaper for a coronary bypass or knee or hip replacement than the US. To assure quality of care many of the brokerages feature international partnerships. Duke University is in partnership with the National University of Singapore for graduate medical school education. Harvard Medical International and Mayo Clinic are partners in Dubai Healthcare City.

Many countries depend on tourism for revenue but medical tourists spend \$362/day compared with \$144/day by an average tourist. Revenue promotes jobs and reduces brain drain because doctors are not as tempted to migrate to developed countries if they can practice at home. What is less well documented is how or if the increased revenue improves local access to healthcare. Turner (2007) suggests that international patient revenue may actually crowd out local patients. "Already in India there are elite, high-quality medical facilities offering healthcare that is unaffordable to all but a tiny segment of local individuals" (Turner, 2007).

In the past, the US was one of the major destinations for cosmetic surgery, but now better opportunities are available in developing nations at more reasonable costs. From 2005-2018 there was a 6-8% reduction in the number of cosmetic surgeries in the US. The Asia Pacific region dominates the global medical tourism market as of 2018. India, Thailand and Singapore are advertising aggressively and effectively. The Bumrungrad International Hospital in Thailand and Apollo Hospitals Enterprise Ltd. in India are top hospitals, accredited by Joint Commission International (JCI). In 2017, an estimated 2.4 million individuals visited Thailand seeking affordable and quality medical care (Global Medical Tourism Market Forecast up to 2025 @ <https://www.infoholicresearch.com/report/medical-tourism-market>).

### Patterns of travel

Historically, people have traveled to sacred springs, holy sites, and consulted with holy persons in hopes of a cure for an illness. In 20<sup>th</sup>-21<sup>st</sup> century medical travel began with patients crossing borders to obtain

healthcare unavailable at home and most of the direction was from developing to developed countries, what may be labeled South to North. At the cusp of the 21<sup>st</sup> century the tide turned and medical travel shifted to North to South and South to South. In 2008, South Americans and Middle Easterners traveled to North America for treatment (Kelley, 2013). Medical travelers from Asian and African countries traveled primarily to Asian Countries, especially Singapore, India, Thailand and Malaysia. The pattern in 2018 is shifting from West to East.

China's massive investment (US \$7.4 trillion) for the Belt and Road Initiative (BRI) is shifting economic growth from West to East and may facilitate a similar change in medical tourism. The BRI connects Asia with Africa and Europe by land and sea, involving over 70 countries. BRI has implications in medical tourism based on expanded transport infrastructure, new high-tech hospitals, and China has signed a memorandum of understanding on medical and health cooperation with the World Health Organization (WHO) expanding cooperation to Belt and Road countries. Consider the reach of BRI covering 70 countries containing 70% of the world's population with 30% of world's GDP and 75% of world energy reserves (Youngman, Ian, 2019, "Get on Board China's belt & road initiative" International Medical Travel Journal @ <https://www.imtj.com>).

### Dynamic pattern of medical tourism

Medical tourism is currently characterized by two patterns: North-South and South-South. Patients from the Global North accessing treatment in private healthcare centers in the Global South is the North-South group. The more populous pattern is intra-regional: 85% of patients traveling to India for medical care are from other southeastern Asian countries (Crush and Chikanda, 2015).

South-South medical tourism, including wealthy clients from neighboring countries going to higher quality private healthcare institutions, mirror the high-end tourism from North to South. The differentiating factor is motivation, distance, and types of procedures sought. In contrast, South-South medical travel is populated primarily by poorer people desperately seeking life-saving interventions that they cannot get at home.

South Africa serves both population trends. For those traveling from the North (UK and Germany) to South Africa, the target market is cosmetic procedures, kidney and stem cell transplantation and fertility treatments. However, South-South travel for medical procedures in S. Africa is growing and includes those who come from a growing middle-class of western and eastern African nations, those sent by government-sponsored medical advisers for specialized treatment unavailable at home, and medically disenfranchised individuals from neighboring countries, such as Mozambique, Lesotho, Swaziland, Botswana, Zimbabwe and

Malawi. South Africa has a better doctor-patient ratio than surrounding countries and is a suitable destination for treatments unavailable at home. The number of medical tourists in this category is growing: from 8,000 in 2003 to 180,000 in 2012 (Crush and Chikanda, 2015). Rapid growth and influx of patients have consequences to equality of healthcare access in South Africa. Denial of treatment is unconstitutional. The regional medically needy population is putting pressure on the South African healthcare system.

### **Neoliberalism influence**

Neoliberalism arose after WWII fueled in economic and philosophical applications leading to privatization, deregulation and commodification of goods. Neoliberalism expects the state (nation) to create circumstances wherein private businesses flourish through low taxes and public funded incentives. Further it relies on market forces to control distribution of goods. Internationally, neoliberalism favors free trade, no tariffs, and competitive business. World Trade Organization (WTO) and structural adjustment programs (SAPs) are shaped by neoliberalism philosophy among the G8 countries who dominate financial and trade organizations. Medical tourism represents a contemporary iteration of the neoliberal philosophy in global healthcare.

Individuals needing a hip or knee replacement or cardiac surgery may not be able to afford the treatment and it is difficult to blame the needy patient for seeking more affordable care. One could suggest that using medical tourism to find a more affordable treatment is wrong because it augments inequality. The greater moral wrong is the systemic inequality of healthcare provision within the US (and such inequality in healthcare access is not unique to the US). The US has a patchwork of employer based private and government-sponsored insurance. Costs are rising and out of pocket expenses are impacting access to care. The rising cost of health insurance premiums is attributable in no small part to the US decision to allow health insurance companies to determine premium rates, including allowing businesses to charge exorbitant rates for covering persons with pre-existing conditions; and the US fails to make caring and just rationing decisions about the use of very expensive 'last chance' medical therapies that offer only marginal benefits, and refuses to control medical care costs. The confluence of these factors, along with a political system marred by partisanship and a culture of patronage that favors special interest groups, such as the health insurance lobby, is responsible for the fact that millions of Americans do not have health insurance in 2010 (Meghani, 2011). Comparing the cost of a procedure between the US and India make the appeal evident: hip replacement in the US averages \$43,000 whereas in India it is \$9,000; heart bypass surgery in the US is \$130,000 vs \$10,000 in India.

India has made medical tourism an export, so tax breaks are given to facilities and their patients. Prices in the public sector have increased while government subsidies to public hospitals have decreased. Meghani (2011) argues that it is not ethically right for a citizen of the US to go to India for surgery to save money because it makes the gap of access to medical care for the rich and poor of India worse. "One should see the harm and not contribute to it; refuse to benefit from damage to others" (Meghani, 2011). She supports this ethical position through a social connection model of responsibility which argues that there is no clear direct link between those harmed and those who benefit. The social connection model of responsibility helps evaluate structural processes that may exploit the marginal or deprive a specific class of people.

Supporting a free market ideology may condone India's decision to invest in medical tourism with private hospitals, owned or in partnership with companies from Australia and Canada and the US, such as the Sir Edward Dunlop Hospital, a US\$ 40 million cardiac care facility in Faridabad. Apollo Hospitals are also financed by international investments.

### **Government investment in medical tourism**

Recognizing the economic value of medical tourism, countries have chosen to become medical tourism destinations. Moghavvemi et al. (2017) analyzed medical tourism facility (MTF) websites for information about hospital accreditation, cost per procedure, visa assistance, accommodations, medical record handling, translation services, post-operative care, patient testimonials and virtual tours. Information varies in content between locations. There is no regulation on what can be posted. Consumers should be aware that this information is advertising-info commercials.

### **What are the policy implications of MT?**

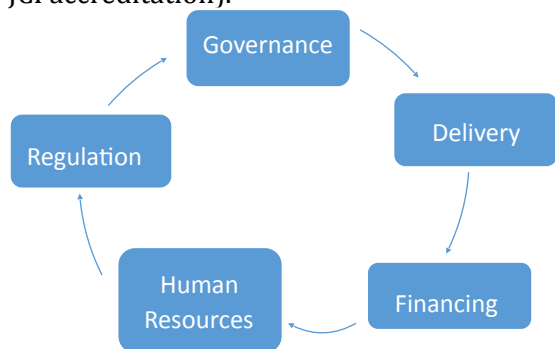
The impact of healthcare access in medical tourism destination countries relative to just access to healthcare within the country is a concern (Pocock and Phua, 2011). With a growing demand for healthcare access, aging populations, increases in chronic diseases and cost of care escalating, the time is ripe for countries to position as medical tourist destinations. Thailand, Singapore and Malaysia were compared using an inductive theory approach. The policy used to frame medical tourism in these countries overlaps policies about trade and health through international mobility, advanced information technology, and expanding the private healthcare sector. However, trade policies and health policies tend to have conflicting objectives.

Regulation of trade under WTO and health under WHO along with regional associations challenge us to reconcile aims of economic growth with equitable health services in countries seeking to grow the medical tourism market (Pocock and Phua, 2011).

WTO requires legally binding obligations for member nations, including no tariff barriers to trade of goods and services and have a mechanism to resolve disputes. In contrast, WHO lacks legal obligations by member nations and has no compulsory dispute resolution mechanism.

Medical tourism is organized under the General Agreement on Trade in Services (GATS) allowing for cross border supply of services, consumption of services abroad, foreign direct investment in health facilities and movement of health professionals. Malaysia, Cambodia and Vietnam have made GATs in the health sector, while other countries trade outside of formal agreements. One advantage of a GAT is that foreign direct investment can be constrained protecting health systems from monopolization. All public hospitals in Singapore are Joint Commission International (JCI) accredited and publicly owned, but in some cases, physicians may operate in a private wing to treat medical tourists. JCI is the most established medical tourist industry accreditor worldwide. It is used to assure quality, but it is also voluntary.

Policy recommendation by Pocock and Phua (2011) constitutes an interactive systemic approach (Figure 1) that deals with governance (policymaking at international, regional and national levels), delivery (private sector growth, foreign investment in healthcare), financing (OPPs organized medical tourism insurance), human Resources (distribution of specialists between private and public sector hospitals, future capacity building), and regulation (public and private sphere quality control through JCI accreditation).



**Figure 1:** Policy creation for medical tourism should involve an interaction of five components in order to provide safety of patients, uniform standard of care, and promote global healthcare.

### Why regulation is a bioethical issue

The medical tourism phenomenon has attracted academic attention as the field expands and policies are crafted to oversee patient safety, global public health, and mechanisms to deal with regulatory issues. Regulatory considerations should consider whether the procedure is legal in home and destination countries, or legal in destination but not at home (such as euthanasia or stem cell tourism). Some destination countries (44 nations as of 2001) include healthcare services of medical tourism under General Agreement on Trade in Services (GATS) as

an extension of the WTO, which has legal obligations among member states with dispute resolution mechanisms (Cohen, 2012). It would be preferable to have more multilateral regulation, through what Gostin (2008) has proposed: a framework convention on global health. Theoretically, WHO has the authority to address epidemic spread of infectious agents. If WHO worked in collaboration with the Council for International Organization of Medical Sciences (CIOMS), they could form a working group like the current focus on vaccine safety and pharmacovigilance, in order to oversee medical tourism. It will take considerable political will to achieve multilateral regulation of medical tourism (Cohen, 2012).

### Healthcare as a commodity

Consumer driven healthcare could lead to competitive pricing to the benefit of patients, but profit driven markets may more likely contribute to inequality of access. Out of pocket expenses are increasing in many countries which is a larger burden for the poor than for the wealthy. In medical tourism, providers compete for patients based on price. US insurers may offer reimbursement of elective procedures done in foreign countries where differential pricing is favorable. Faced with paying for a needed operation, individuals who cannot afford treatment at home will benefit from lower priced care abroad.

The US, Mexico and Turkey are the only countries among 30 industrialized nations that do not offer universal healthcare. Organization of Economic Cooperation and Development (OCED) reports that spending in the US in 2007 for healthcare averaged \$7,290 per person per year compared to an average of \$3,000/per person per year among other industrialized countries and is projected to reach \$13,000 per capita in 2019. OECD health statistics for 2019 were released July 2, 2019 ([www.oecd.org/els/health-systems/health-data.htm](http://www.oecd.org/els/health-systems/health-data.htm)). In 2017, the US spent 8.8% of GDP on health. According to the Centers for Medicare and Medicaid Services (CMS) "the average American spent \$9,596 on healthcare in 2012, "more than twice the per capita average of other developed nations." It averaged \$10,345 in 2016 and is expected to go up annually. United States Department of Health and Human Services (USDHHS) estimates health spending will reach 4.5 trillion dollars by 2019 (29% GDP). Drivers for increased cost include technology, drugs, independent profit motives, aging population and increase in chronic disease.

Kumar et al. (2012), addressing the impact of medical tourism on the supply chain of healthcare in the US, framed three questions intended to guide an ethical discussion of medical tourism and to shape public policy. What are the inefficiencies in the various US healthcare systems that are leading to increasing costs? The answer is new technology, high administrative costs, increased pricing of pharmaceuticals, and an escalation in the number of

residents with chronic illnesses. The second question is: What are the factors that potentially influence US citizens who are considering medical travel? In an age of the internet and global access to information, individuals seeking a specific procedure or treatment for a medical condition can consult the Web. [MedicalTourismAssociation.com](http://MedicalTourismAssociation.com); [healthbase.com](http://healthbase.com); [health-tourism.com](http://health-tourism.com) each offer advice about where to go for specific types of care.

The third question by Kumar et al. (2012) is: What are the overt and hidden supply chain benefits and costs of exporting medical procedures overseas? And what are the long term ramifications of promoting a global healthcare supply chain? The cost savings per procedure and the number of procedures done for US citizens reveal significant savings for the medical cost of care for both patient and insurance company and a large increase in revenue for the destination country. Kumar compared cost of three procedures (knee and hip replacement and heart bypass surgery) in India, Thailand and the US. Using information from Medical Tourism Association to estimate the number of US residents traveling for medical procedures, and cost comparison based on Monte Carlo simulation with variability encapsulated by triangular distributions, Kumar et al. (2012) estimate that in these two destination countries, US citizens will spend 20-30 billion US dollars.

Twenty billion dollars of cost savings or lost revenue is a wakeup call to medical stakeholders including hospital administrators, insurance industry executives, members of US Congress, Medical School Deans, and Pharmaceutical industry officials. The implications for US healthcare is that unless ways are found to eliminate waste and other inefficiencies and curb rising costs, the nation will continue to lose revenue to foreign health providers. This means the domestic healthcare supply chain must improve or patients will seek competent and less expensive medical care overseas. It is difficult to predict what the longterm ramifications of a global healthcare supply chain may be (Kumar, et al., 2012).

### **Global impact on public health**

Global documentation of medical tourism is fragmented and incomplete. Countries seeking to be medical tourism destinations record incoming patients whereas their home countries may have no records of their going abroad for a medical procedure. Insurance or other co-payers may know of medical tourists for purposes of reimbursement or treatment of complications after returning home. Data for quantitative analysis of effectiveness for patients' wellbeing is incomplete, making it more difficult to measure risks and benefits (Turner, 2013).

A robust ethical assessment of medical tourism at the individual patient level should focus on beneficence to patients but as regards to public health, global medical tourism needs to evaluate the impact on destination country citizens' access to

healthcare. Qualitative assessment of care and public safety is an ethical concern among and within countries. Post-surgical complications occur, and it is unclear if more occur in medical tourism than in traditional contexts. Concerns about skill level and international standards of care should be addressed through JCI and WHO. Lacking a regulatory framework within WHO, the World Medical Association (WMA) does have influence through CIOMS and this could be expanded to address quality controls for medical tourism.

Travel has inherent risks, such as pulmonary embolism and thrombosis which occur post surgically and have an increased risk with air travel. It should be clear to medical tourists what preventative measures to use to reduce the risk. Individual case reports highlight the risk, but quantitative analysis has not been done to document if medical tourists as patients have a higher risk than ordinary travelers or post-operative patients (Snyder et al., 2013). Medical tourists rarely travel alone for a medical procedure. Caregiver companions are another stakeholder in this industry (Casey et al., 2013). Risk to companions deserve further scrutiny.

Infectious diseases are a public health concern as they spread quickly by international travel. One patient who had a kidney transplant in India returned home with Hepatitis B and infected eight others locally (Turner, 2013). Multi-drug resistant bacteria (MDR) and pathogenic viruses are easily transmitted in crowded conditions, such as plane travel and in hospital environments. Medical travel could increase transmission of MDR bacteria, but again more quantitative data is needed to document the frequency and sites for more informed consumer choice and for action by public health officials.

### **Conclusion**

Overall, medical tourism is a growing market industry fueled by technology. It has the potential to improve global health by offsetting inequalities of medical care access and standardizing quality of care. To become a positive rather than a negative force in healthcare, several concerns should be monitored quantitatively and addressed in new ethical guidelines: safety and quality of care for patients, more just access to standard treatments, public health monitoring for spread of infectious diseases, data capture of all medical tourism for quantitative analysis, and assessment of impact on the gap of inequality in price of treatment within and among countries (Casey et al., 2014; Adams, et al., 2017; Connell, 2011).

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## Experiences of a Japanese couple following fertilization with a donated egg: the husband's narrative

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### Abstract

The objective of this study is to understand the experiences of husbands whose wives have conceived via donor eggs, before the birth of their child. Participants of this study were recruited through newspaper advertisements, through queries for Japanese husbands who would volunteer for this study. Data were analyzed through a qualitative method. A semi-structured interview was conducted with a Japanese man married to a woman who became pregnant with a donor egg. The narratives were "the decision to receive treatment with donor eggs," "a genetically unrelated child," "the struggle with the ethical question of receiving a socially unacceptable treatment," and "informing a child about the truth of his conception." When Mrs. X became pregnant, Mr. X had worries and anxieties over whether or not his wife would be able to love the genetically unrelated child. This is considered an issue of the family norms in modern Japan.

### Introduction

Japan leads the world in the use of assisted reproductive technologies (ART). Women who receive these treatments are older, peaking at the age of 40.<sup>1</sup> According to a national survey, the mean age of egg recipients is 45.2, with some recipients being over the age of 55. The number of children conceived via donated eggs is estimated to be 300 to 400 annually.<sup>2</sup> The International Fertility Center (IFC) reported that more than 1,500 Japanese couples have given birth to a child through egg donation, and the rate of pregnancy for those who have received these donations is 75 percent<sup>3</sup>. However, the use of ART through third-party

donation is prohibited by Japanese Society of Obstetrics and Gynecology.<sup>4</sup> For this reason, the Japanese Institute for Standardizing Assisted Reproductive Technology (JISART),<sup>5</sup> which consists of 30 ART clinics, developed its guideline for prescribing ART to women who cannot have their eggs extracted for medical reasons. Fifty-six children have been born through this procedure through 2018. However, since JISART has excluded women who are infertile because of their age, women who are around 50 years of age or older and cannot conceive on their own must travel abroad to receive treatment using donor eggs.

Popular travel destinations for Japanese couples seeking treatment include the United States, Malaysia, Taiwan and Thailand. Since medical costs for this treatment in the United States are high, couples are increasingly receiving treatment in countries where medical expenses are more affordable.<sup>6,7</sup> Dozens of agencies have emerged that target Japanese couples, some of which have poor reputations after receiving negative reports;<sup>6</sup> The majority of Japanese women who become pregnant with donor eggs have given birth in Japan. It has been pointed out, however, that some are unaware that their pregnancy could be a high-risk pregnancy,<sup>8</sup> and the number of such cases will only increase unless perinatal outcomes for older women are investigated and feedback is gathered.<sup>9</sup> Furthermore, there are complex issues to be resolved, including the physical burdens of donors (such as the side effects of egg extraction), the legal status of newborns, and children's right to learn the identity of their genetic parents.<sup>9</sup>

The majority of Japanese couples who are considering ART or who have previous experience with this treatment do not get introduced to overseas agencies from the facilities where they are receiving fertility treatments; instead, they collect information by consulting websites and social networking services to determine the country in which to receive treatment.<sup>6</sup> Those who have experienced treatment using donor eggs have identified a range of issues, including medical costs, problems arising from differences in language and culture, the absence of facilities for delivery, and the lack of follow-up care after pregnancy.<sup>2</sup>

In Japan, research into ART with donor eggs has consisted almost entirely of surveys of trends in reproductive tourism or analyses from legal, ethical, and medical perspectives. There are only a few studies of families that have formed as a result of this treatment. Moreover, all of these have focused on women; no studies have been conducted on men.

### **Study objective**

The objective of this study is to understand what it is like for a husband to form a family by means of transnational egg donation, through the experience of a husband (Mr. X) whose wife (Mrs. X) has conceived via donor eggs.

### **Study methods**

Participants for this study were recruited through newspaper advertisements; Japanese husbands who volunteered for this study were queried. Data were analyzed through a qualitative method, after the author conducted 60-minute semi-structured interviews in 2014. Interviews were recorded on an IC recorder with the approval of the participants and transcribed verbatim. The transcriptions were read carefully, with a focus on the events and the thoughts and feelings of the husbands, beginning with the reception of donor eggs and continuing until the birth of their child. Condensed meaning units were abstracted and labeled with a code. The codes were compared, and those that conveyed similar meanings were categorized together in order to develop themes that were related to their experiences. In the course of analysis, advice from experts in qualitative research was received. The present study was conducted with the approval of the research ethics committee of the Niigata University Graduate School of Health Sciences.

### **Results**

Both the husband and wife were in their 40s (they were married in their 20s). For medical reasons, Mr. and Mrs. X had no choice but to receive eggs from a third party abroad in order to have a child. The husband and his parents wanted a child, and the parents covered all expenses for travel and medical treatment. The data analysis resulted in four main themes: "the decision to receive treatment with donor eggs," "a genetically unrelated child," "the struggle with the ethical question of receiving a socially unacceptable treatment," and "informing a child about the truth of his conception." A description of Mr. X's experience follows; his words are in quotes.

#### **The decision to receive donor eggs**

Because Mrs. X was infertile, Mr. X had been considering what problems might arise after receiving eggs from a donor. He searched for information on egg donation on the Internet and read the blogs of people who had received such treatments, without telling his wife. He perceived that social changes had occurred because domestic media had started to feature stories of surrogate delivery and pregnancy via donor eggs in the United States. Since travel and medical expenses were costly, Mr. and Mrs. X did not think they could afford the procedure based on their income. However, Mr. X's parents offered to cover the medical expenses; thus, treatment with donor eggs became an option for them. Mr. X was familiar with various problems that might occur after pregnancy using donor eggs because of his research online, and he believed it was important that both parents should be aware that the pregnancy would be the result of egg donation. When Mrs. X consulted her parents and expressed her desire to receive the treatment, they



immediately approved. Since most overseas facilities offering fertility treatments do not have agencies in Japan, Mr. and Mrs. X searched for agencies online. Mr. and Mrs. X decided on an agency and asked them, without much hope, to explain whether they legitimately provided treatment with donor eggs. Hearing their explanation, Mrs. X was assured of their reliability and became suddenly enthusiastic about the treatment. Mr. X thought, "I wanted to seize this opportunity to proceed with treatment." Mr. X said he was eager to travel abroad immediately to have a child. However, he considered the feelings of Mrs. X, who was going to give birth to a child to whom she was not genetically related; he gave due regard to Mrs. X, allowing her to decide whether she would receive the treatment.

He said, "When I considered my wife's feelings, I couldn't get in gear with egg donor treatment via a third party. Though it may sound cowardly, I arranged things so that it was ultimately up to her whether or not to receive treatment. That's what I prioritized over everything else."

### **A genetically unrelated child**

Mr. X was more anxious than delighted when his wife became pregnant. He continued to be concerned, until the birth of the child, whether his wife would care for the genetically unrelated child and whether she would develop maternal instincts without guidance from an experienced parent. Mr. X said he had acted cautiously so as not to hurt Mrs. X's feelings, especially because the child would be genetically related to him but not her. Through the pregnancy, Mr. X completely refrained from touching her belly or talking to the child until the child was born. Mr. X was prepared to live with the child even if Mrs. X was incapable of loving the child. Mr. X continued to reflect on these concerns but did not communicate them with Mrs. X.

He noted, "I was very concerned whether my wife would work with me to raise a child who was genetically unrelated to her and behaved cautiously (treating her with kid gloves), thinking of how I might interact with her without being offensive."

### **The struggle with the ethical question of receiving a socially unacceptable treatment**

In Japan, there are no legal restrictions on the use of ART. However, Japanese Society of Obstetrics and Gynecology prohibits ART that uses donor gametes. Mr. X continued to struggle with the ethical question of whether it was right or wrong to create life via a treatment that was not socially acceptable in Japan.

He stated, "I was unable to proceed with the treatment. Though I had heard of egg donation treatment, I was not sure how to answer the ethical questions surrounding this treatment or how I would treat my child if he were to find out about it in the future."

### **Informing the child of the truth of conception**

Mr. X decided to keep the egg donation a secret and thought it unnecessary to inform the child, as the child resembled him. However, he said that if the need to inform the child arose in the future, he would leave it to Mrs. X's judgement.

He said, "I am not going to tell him the truth. I will take the secret to the grave. After my parents die and then we die, no one will know the secret."

## **Discussion**

### **Leaving the decision to receive treatment to the wife's judgment**

Mr. X was eager to begin treatment without missing any opportunity to receive a donor's eggs. However, he left the decision to proceed to Mrs. X's judgement. This may be understood as Mr. X's respect for Mrs. X's feelings being greater than his desire to have a child of his own. In the case of donor egg treatment, the mother must make a major decision regarding whether or not she will be able to deliver and rear a genetically unrelated child. Furthermore, because donor egg treatment has not been accepted by Japanese society, it is essential for the prospective mother to make this decision from the perspective of reproductive health and rights. Although an increasing number of couples in Japan travel abroad to receive treatment, there have not been sufficient social discussions about issues such as the risks associated with pregnancy at an advanced age ( $\geq 45$ ),<sup>10</sup> physical burdens on the donor, children's right to know or to refusal to know their biological parents,<sup>11</sup> what information the child should be given about the donor, and the counseling needed before parents decide to travel abroad for treatment.<sup>9</sup> Moreover, the difficulties parents with a child from a donor egg will face in the future are unknown; they may encounter unexpected events and emotions. These situations suggest that the information necessary for deciding whether or not to receive donor egg treatment is not readily available. Thus, couples who are considering donor egg treatment must have the determination to persevere together through potential hardships in the future.

### **A family not dependent on genetic relatedness**

Mr. X received approval from Mrs. X's parents as well as his own to proceed with donor egg treatment. Receiving donor egg treatment after couples have first obtained approval from their respective parents has some benefits for couples. First, if no one other than a couple knows that they are having a child using a donor egg, they may worry that their parents will point out that the child's appearance does not resemble the mother's.<sup>12</sup> If the couple's parents know in advance that the child was born from a donor egg, this problem does not arise. Second, if the child becomes skeptical about his origin or his parents are worried about how to raise their child, they will be able to consult their parents. Third, since

the child will not inherit Mrs. X's genes, knowing about the donor egg in advance will give a couple's parents a period during which they may prepare psychologically to accept the child, as seen with the parents of the couple in this study. This will facilitate support for the new family that might not arise naturally because it does not adhere to traditional Japanese notions of biological parenthood.<sup>12</sup>

With the advances in ART, combined with medical technologies, various family structures have emerged: heterosexual couples, single parents, and gay and lesbian couples, all of whom are able to have children and start a family.<sup>13</sup> Although Japan has witnessed a rise in new families that do not adhere to traditional notions of biological parenthood,<sup>12</sup> such cases are limited in number. In the case of couples with a child born from a donor egg, Japanese civil law recognizes the woman who gives birth to a child, genetically related or not, as the legal mother and the couple as the legal parents of the child. However, as many couples have been raised in a family with biological connections, they may occasionally feel embarrassed by the fact that the child was born from a donor egg or experience unexpected events related to this in the course of rearing the child.

### Genetically unrelated mothers and children

Mr. X continued to be anxious about whether Mrs. X would love a child genetically unrelated to her. In the case of conception from egg donation, while the prospective father is genetically connected to the expected child, the mother who gives birth to the child is not. It is the norm of modern Japanese family to more highly regard and give priority to genetically related parents over foster parents.<sup>13</sup> This may lead to anxiety over the relationship between the donor recipient mother and the child. Studies of a few Japanese mothers who started a family from a donor egg reported that pregnant women do have worries and anxieties over the prospect of being able to love a genetically unrelated child.<sup>12,14</sup> This is the first study in Japan to reveal that prospective fathers have similar anxieties as mothers.

During the modernization of Japanese society in the Meiji period, it was determined that an *ie* (family home) can be established only through genetic connections, and a notion developed that the only unrelated individuals who could be included in a family were a "bride" (a son's wife) or a "groom" (a daughter's husband); adopted children were the only exception.<sup>15</sup> For husbands and wives who grow up in a culture in which it is desirable for matrimonial love to produce children, it may be natural for the couple to worry whether they will be able to love a genetically unrelated child. However, reports based on the experiences of those who have started families through donor sperm or adoption claim that parent-child relationships are not necessarily dependent on genetics; time spent together as a family establishes psychological intimacy.<sup>16</sup>

In contrast, Mr. X absolutely refrained from talking about the coming child with Mrs. X during

her pregnancy. This kind of situation has not previously been observed during pregnancy among couples undergoing ART treatments;<sup>17</sup> it can be interpreted either as an embodiment of the care the husband took to prevent his pregnant wife from feeling alienated or as his unwillingness to remind her of his genetic connection to the child, a connection she did not share. Little is known about the emotions that prospective fathers feel in the process of starting a family via egg donation.

### Informing the child of the truth

Advances in ART have promoted the formation of families of various types. Mr. X was determined not to inform his child of the truth from the beginning. His child resembled him, which led Mr. X to believe that both his acquaintances and the child would not doubt that they were biologically related, confirming his strategy of not telling the child the truth. This line of thinking is indicative of the significant effect of social conventions on families, to expect genetic connections. If the baby does not resemble either the husband or the wife, the family may worry that their acquaintances as well as the child may suspect that they are not genetically related.

In Japan, there has been a call to recognize the legal right of children conceived via donor insemination (DI) to learn the truth of how they were conceived. Children's rights to know or to refuse to know have not been legislated yet. In Japan, more than 60 years have passed since DI was first carried out with donor sperm, and more than 15,000 children are born annually through this procedure.<sup>18</sup> Since sperm donors are anonymous in principle in Japan, most children are not informed that they were conceived using DI. However, some children, who have learned that they were conceived via DI, have expressed concerns that arose subsequently in critical situations such as the death of a parent or divorce, as well as concerns over no longer trusting their parents after reaching adulthood and learning the truth.<sup>19</sup> Furusawa et al.<sup>20</sup> argue that behind the hesitation of the parent to tell a child the truth lies a stigma attached to families that use DI, arising from social conventions that expect parents and children to have genetic connections. On the other hand, children conceived via DI are hurt because their parents wish to keep the use of the medical technique a secret from those around them.<sup>19</sup> Treatment using donor sperm and treatment using donor eggs are similar in that, in both cases, the mother delivers a child. However, in the case of donor eggs, the conflict the couple faces when endeavoring to inform the child of the truth is more difficult in Japan where a mother who becomes pregnant with and gives birth to a genetically unrelated child is nevertheless treated as the legal mother of the child even though the father is genetically related and the mother is not. Some couples who became parents via donor eggs are reported to have the intention of informing their children of the truth.<sup>12</sup> An increasing number of

couples are starting a family with donor eggs, yet little is known about their experience. It is therefore necessary to conduct additional studies in order to discover their views and identify medical and social challenges.

### Conclusion

Mr. X left the final decision of whether or not to proceed with egg donor treatment up to his wife. It is important from the perspectives of reproductive health and rights for a prospective mother to decide for herself. However, the information needed to make such a decision is not readily available in Japan. Thus, couples receiving treatment must have the determination to persevere together through potential hardships.

Mr. X obtained approval for donor egg treatment from both his parents and his wife's parents. This not only gave the couple's parents time to prepare psychologically to accept the child, but it also facilitated support for the new family who did not adhere to the traditional Japanese model of biological parenthood.

When Mrs. X became pregnant, Mr. X had worries and anxieties over whether or not his wife would be able to love the genetically unrelated child. This is considered an effect of the family norms in modern Japan. Moreover, as many couples with children from egg donation treatment have been raised in a family consisting of biologically related members, they may occasionally feel embarrassed that the child was conceived via a donor egg or experience unexpected events in the course of rearing the child.

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## Historical and modern aspects of Islamic philosophical, religious and ethical traditions in medicine in Uzbekistan

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### Abstract

This article provides a brief presentation of the traditional sources of Islamic bioethics, the spiritual basis of the Muslim medical code, the role of fundamental methodological sources in the Uzbek model of bioethics, a study of key bioethical problems in the context of the teachings in Koran, Sharia, and Hadith and their transformation in the late twentieth century in relation to sensitive and complex medical and biological problems in Islamic medical ethics and bioethics.

### Introduction

The addressing this subject is due to the tasks set in a presidential decree in the Republic of Uzbekistan on 20 April 2017, over "measures for further development of the system of higher education" and other decrees that have a wide impact on the educational process in the curriculum and teaching materials based on international educational standards related to the course of bioethics. The main concerns in the course of bioethics are topics related to the presentation of modern philosophical orientations and humane cultural values associated with delicate issues that emerged after breakthroughs in biomedical technologies: issues of life and death, biomedical research involving human subjects, medical genetics, genomic medicine, etc.

The subject "bioethics" refers to a social and humanities course which requires knowledge in the field of philosophy, history of medicine, religious studies, history of Uzbekistan, law, public health and healthcare, clinical genetics, and others. Modern biomedical ethics is based on a rich tradition of systematic moral thought, both philosophical and religious. Nowadays, in the 21<sup>st</sup> century, the interaction and synthesis of natural and humanitarian disciplines is of paramount importance in the system of medical education. One of the ways to solve this problem for future specialists is to learn the basics of biomedical ethics.

The first bioethics research Institute, the Hastings Center, was established in June 1969 in New York. In 1971, Georgetown University in Washington established the Joseph and Rose Kennedy Institute of Ethics, which in turn opened the Bioethics Center

and published the first "Encyclopedia of bioethics" in 4 volumes in 1978 (the last edition was published in 2005). These were the first steps towards the institutionalization of bioethics, which can be compared to the current number of bioethical organizations around the world. The total number has long exceeded one hundred; the largest centers of bioethical research are located in Australia, the UK, Canada and the USA. As an academic subject, bioethics has become a standard part of international educational in philosophy and medicine. The priority of philosophical training for medical students is to help form their creative thinking and scientific outlook to become free and responsible persons able to work constructively in problematic situations, combining professional competence with civil responsibility.

Currently, Uzbekistan pays special attention to creating conditions for further improving the quality of medical services in all regions of the country. To implement this task, it is important to build a bioethical culture with future doctors. The development and study of bioethics will help to formulate new ethical postulates, push them to the medical and scientific community, and understand better the moral dilemmas faced by doctors, medical staff and researchers not only in their daily work, but also in the development of the latest biomedical technologies. It is physicians who first of all face the problems of biomedical technologies and their consequences. The presence of these problems and solving them is directly linked to the physical, mental, social and spiritual health of people. The solution of these problems is envisaged in the future in the priority areas of the strategy for 2017-2021. The search for new value foundations of biomedical ethics, such as compassion, charity, harmony, and solidarity continue the ancient spiritual traditions which were first introduced by Arab-speaking scholars of the West and Central Asia.

Modern biomedical ethics is based on rich philosophical and religious traditions and maintains historical continuity with traditional professional medical ethics (Mukhamedova, 2015). The rapid growth of problems related to the progress of biomedical technologies in the West led to the emergence of medical ethics. The origins of the bioethical teachings of Western philosophy are undoubtedly of great importance in the formation and development of Islamic bioethics and many of its concepts. However, in a period of 35 years during which Islamic bioethics has been developing in Uzbekistan, its features and priorities have appeared in not only religious consciousness, but also socio-cultural, philosophical, legal and other aspects.

The role of Islamic bioethics in the development of global bioethics should be noted; the significance of the great scientific, medical and philosophical heritage left by Arab-speaking scientists in West and Central Asia. A clear recognition of this historical fact is the establishment of the Avicenna prize for research in the field of ethics by the UNESCO

Executive Council in 2004, as well as the proclamation of the city of Tashkent as one of the three capitals of Islamic culture in 2007 by the International Islamic Organization for Education, Science and Culture (ISESCO). The program honoring the capitals of Islamic culture was approved by ISESCO in 2001 and involves the annual election of three capitals representing three Islamic regions – the Arab world, Africa and Asia. Bukhara has been recognized as the capital of Islamic culture in 2020. This decision was made at the ninth conference of ministers of culture of the state members of the Organization of Islamic Cooperation (OIC). In addition to Bukhara, Cairo (Egypt) and Bamako (Mali) were approved as the capitals of Islamic culture in 2020. In fact, Bukhara has been the capital of Islamic culture for several centuries. In the Muslim world, Bukhara has firmly established the epithets "Kubbatul Islam" and "Gunbadi Islam", which mean "Dome of Islam" in Arabic and Farsi. The fact that the city was recognized as the capital of Islamic culture once again confirms the outstanding contribution of this city and its scientists to the development of Islamic civilization.

### Materials and methods

The purpose of this study is to examine the ancient sources of bioethics of Islam, which may include the practical ethics by Dr. al-Ruhawi (Ishaq ibn Ali Al-Ruhawi), the "Canon" of medical science by Avicenna, "Adab Al-Tabib", "Spiritual medicine" by Ar-Razi, and many others that have become the classics in the annals of medical ethics. This knowledge continues to form the spiritual basis of Islamic medical code, bioethics, environmental and biomedical ethics. Here, special attention is given to the role and significance of the Eastern tradition of philosophy based on Islam, and its syncretism (indivisibility) with the doctrine of proper behavior of a well-raised person, "adabnoma". The methodological basis is general scientific methods, historical and comparative analysis. The works by B. A. Zikria, Hassan Chamsi-Pasha, Aksoy S. Karaman H. Abu Bakr Al Razi, Omar Hasan Kasule, Ben Hamidaf, Mohammed Ghaly, Abul Fadl Mohsin Ebrahim and others are used in this article. This study demonstrates the fundamental methodological sources of the Uzbek model of bioethics.

### Results and Discussion

The syncretism of the Eastern tradition of philosophy has created a term that has no analogues in European culture - "adab", the doctrine of proper behavior of a well-raised person - "adabnoma". It combines general education, the theory of morality and rules of behavior, which can be simplified to education, with the formation of an ideal person of the East, "Kamil Inson". The fundamental methodological sources of the Uzbek model of bioethics include the Central Asian codes of behavior "Kobusnoma" by Kaikovus, the treatise "on Ethics" by Ibn Sina, "Four conversations" by Aruzi

Samarqandi, "Code of decency in the East" by Sadiq Kashgari, and many others.

The distinctive feature of Muslim medicine was its ethics. Muslim hospitals served people regardless of religion, color, or origin. The hospital staff treated all believers equally, whether they were Christians, Jews, or other confession. The Muslim doctor was called "Hakim", which means "wise" in Arabic. Muslim doctors were deeply religious and practiced in the name of God.

### Classical sources and examples of medical ethics that make up the spiritual basis of Islamic medical code

Inspired by the ancient heritage of Hippocrates in the field of medical ethics, Ishaq Ibn al-Ruhawi, Ar-Razi, Ibn Sina, Maimonides created an open system of moral values, Adab al-Tabib. In contrast to European neo-Hippocrates, the Adab al-Tabib value system is flexible and multifunctional. It can also adapt to the knowledge of bioethics in the twenty-first century.

Back in the 9th century, the physician Ishaq bin al-Ruhawi wrote the first treatise on medical ethics, Adab al-Tabib. In this treatise, Ruhawi refers to doctors as "guardians of the soul and body", and observes and analyzes the behavior and deeds of a Muslim doctor (Zikria, 1967, translated by Martin Levey). Al-Ruhawi accomplished a lot in his work in order to "humanize" medicine, considering the problems of relationships with patients. He believes that the purpose of the doctor is to bring good and well-being to the human race in general, not only to friends, but also to enemies. God made doctors swear not to invent poisons (Chamsi-Pasha, Albar, 2013; Aksoy 2004;3:9-11). Al-Ruhawi quotes Aristotle, Socrates, Galen, and Hippocrates and supports their ideals, but Adab al-Tabib is primarily a text based on Muslim traditions and beliefs. Adab al-Tabib is not only a guide to professional ethics, but also contains important information about personal hygiene, a patient doctor, and provides an explanation of the relationship between the profession and society. (Chamsi-Pasha, Albar, 2013; Aksoy 2004;3:9-11).

Adab al-Tabib consists of 20 chapters, which are divided into 3 categories: 1) the behavior of the doctor, 2) the behavior of the patient, 3) the attitude of the society to the medical profession and to patients. The content of Adab al-Tabib considers the doctor's personal beliefs and practices, attaches great importance to his faith in God, personal health and hygiene, as well as his manner of dealing with colleagues and patients. Al-Ruhawi emphasizes the importance and role of patient authority and respect, even though the doctor has to ignore patients' wishes when it is necessary for their health. He says that doctors should occupy a high position in the social hierarchy; their work should be well paid, so that the doctor does not look for some other job, but doctors should not flaunt their wealth. Al-Ruhawi says that the costs charged to rich patients

should be sufficient to cover the costs of poor patients who cannot pay for themselves, and medical care should be equally good for both rich and poor.

In *Adab al-Tabib*, al-Ruhawi talks about legislative practices and punishments for lying and incompetence of doctors. Inspired by Galen's work, he advocates the practice of medical exams and licenses. He encourages doctors to keep a record of the patient's symptoms, treatment, and recovery. Al-Ruhawi recognizes that the recovery of patients is not always manageable, and if the patient is doomed, he must die under the care of a doctor. Al-Ruhawi suggests extreme punishments even the death penalty for doctors who allow patients to die because of their negligence and incompetence.

Another great physician, philosopher, and scholar of Islamic civilization, Abu Bakr Muhammad Ibn Zakaria al Razi (865-925), wrote more than 200 books on various subjects (Karaman 2011; 30: 77-87). In the history of Islam, Razi is considered the only doctor who can be compared to Abu Ali Ibn Sina. Razi was a therapist, but also had a lot of experience in surgery. Razi wrote the book "*Hawass ut-Tallis*", which explained the objectives for medical students. The most famous book in the history of Islam on medicine is "*al Hawi*", which includes various experiments and clinical observations of Razi in Baghdad and Rhea. Many authorities in the field of medicine consider Razi's works "*Al Hawi*" and "*Al-Mansuri*" to be the biggest and oldest textbook. Razi wrote the book "*For those who can't get a doctor*" ("*Man lajuzarukh ut-Tabib*") for general use; this is general medicine. The basis of the philosophical concept of Ar-Razi is the doctrine of the five eternal principles: "creator", "soul", "matter", "time", and "space". The atomism of Ar-Razi is close to the atomism of Democritus. He wrote the book "*Measles and smallpox*", on signs and symptoms, and explained the necessary prevention from these diseases. In this book, for the first time, he spoke about infectious diseases and described chicken blindness. Razi has been known as a friendly and generous doctor. He did not let the patients go until he identified the disease, he was very friendly to the poor and provided them with free medicines and food. He could amass a huge fortune, but did not strive for it, and was always absorbed in the study of science.

Razi's most famous book is *al-Hawi*, which includes a complete course of medicine from the ancient times up to his time. He expresses his point of view on each issue. This book has become famous as the most famous book on medicine in the history of Islam, which includes various experiments and clinical observations. The book by Ar-Razi *Ahlak al-Tabib*, presents a model of Muslim medical ethics (Karaman 2011; 30: 77-87). For a doctor, it is important not only to be a professional, but also to be an example in all respects. His ideas in medical ethics were divided into the following concepts: doctor's responsibility to the patient, patients' responsibility to themselves, and patients'

responsibility to the doctor. According to Ar-Razi, a doctor, while practicing, should continue to improve his education and strive to obtain new knowledge. He recommends that doctors be virtuous, humble, and strive to earn the respect of their patients. A doctor has obligations to patients. First of all, in showing compassion, a doctor must be attentive and kind.

Following the Hippocratic Oath, Ar-Razi believed that the second duty of a doctor is to keep the secret that he learned during the treatment of his patients. Another duty of the doctor is to support the patient in every possible way morally and psychologically, to inspire him with hope for recovery, even if there is no hope. The doctor must, according to Ar-Razi, treat all patients equally, regardless of their wealth. The goal of the doctor should not be money, but the treatment itself and the patient's health. Doctors should pay attention to the treatment of the poor and homeless. On the other hand, the patient also has responsibilities to the doctor. So, the work of al-Ruhawi *Adab al Tabib* is a great illustration of the problems of professional responsibility and ethical dilemmas that are still relevant in medicine today.

*Ahlak al Tabib* Abu Bakr Muhammad Ibn Zakariya Ar Razi, who received the title of Galen of the Arabs, is undoubtedly one of the most outstanding achievements in medicine. A work written during the Eastern Renaissance, it provides guidelines not only for enriching the theory of bioethics, but also serves as a guide to action, and functions as a mechanism for humanizing modern medicine and healthcare. The bioethical basis laid down in it, in which medicine and a decent way of life form a single philosophy of health has not lost its relevance today; moreover, it is in many ways ahead of our ideas about the ethics of the physician.

By equipping the doctor with knowledge of the laws and principles for spiritual transformation, Ar-Razi and Ibn Sina create a philosophical basis for the behavioral standards of both the doctor and the dying patient. Islam regulates all spheres of life, determines not only cultural, social, and legal issues, but also penetrates into the interpersonal relationships of members of the Muslim community. The social, legal, and economic aspects of ethical issues and key issues of bioethics in the field of health, medicine, and biomedical technologies in the context of Islam continue to be studied. Bioethical research is actively continuing in Iran, where Sharia law is the law of the state. At the beginning of the XXI century, Iran adopted a package of documents related to transplantation, criteria for brain death (in 2000), and therapeutic abortion (in 2005).

Modern Muslim medicine and bioethics have developed within the framework of enlightened Islam and medical ethics. However, despite the current practice of Muslim bioethics, there are problems and contradictions, starting with the recognition or non-recognition of its status (Mukhamedova, 2006, 2009).

The world religion of Islam has common sources: the Koran, Sharia, and Hadith. Islamic medical ethics both in the past and present rely on the tradition and the law of Islam. At the same time, it is necessary to consider some existing internal differences in the philosophy and theory of Islam and its legal schools. Therefore, there are not only external differences with the main Western philosophical theories and perspectives on medical ethics, but also internal ones, due to different trends in Islam itself. Therefore, before considering the main principles of Muslim morality in the field of biomedical ethics, it is necessary to point out the various sources of the law of Islam.

Sharia is a set of canonical laws of Islam covering all aspects. At the core of Sharia there is the Koran as the Holy book of Muslims; Hadith- stories about the deeds and statements of prophet Muhammad. In addition, lawyers use other sources of Muslim law, including "Istislah" - common interests; "Rie" - your own opinion; "Kiyas" - judgment by analogy; and "Ijtihad" - ability and right of interpretation.

The biological revolution of the last decades has posed new and serious challenges to humanity. What is the attitude of Muslims to these problems? The absence of the institution of clerics in Islam makes it difficult to find an answer to this question: the believer is responsible for the decision. "Ijtihad" allows a Muslim believer to comprehend the problem and change the attitude to it, considering the new circumstances that arise in connection with new achievements in medicine, biology and biotechnology.

The key elements of biomedical ethics in Islam are the concepts of human personality and death. The idea of the human person determines the attitude of the believer to abortion or childbirth with the help of medicine. Organ transplantation is associated with the determination of death, especially in cases where the vital organs of the deceased donor are involved. The same definition is associated with the choice of intensive care and euthanasia.

### **Research on key issues of Islamic bioethics: modernity**

Research on the key problems of bioethics in the context of the teachings of the Koran, Sharia and Hadith, including a large historical experience in the field of medicine in the Renaissance era of Arab and Central Asian scholars, began to transform in the late twentieth century in response to sensitive and complex biomedical problems. In the development of Islamic bioethics as a new form of scientific knowledge in the twentieth century, the establishment of the Islamic medical science organization IOMS and the holding of the first (1981, Kuwait) and second conference of the Islamic medical science organization in Kuwait (1982), where the code of Islamic medical ethics was adopted, are of great importance. The adoption of the code at the second international conference of

the Islamic organization of medical science in 1982 was a starting point in the development of Islamic bioethics. The code consists of thirteen parts that combine ancient and modern ethical teachings, traditions of Eastern medicine, Islam, and philosophy. The code defines the medical profession, the doctor's oath, regulates doctor-doctor relations, doctor-patient relations, doctor-society relations, biotechnological progress, medical secrecy, and doctor's duties and responsibilities in wartime. Special attention is paid to the sanctity of human life, medical education, and issues of Islamic medicine. Here are some excerpts of the doctor's oath: a doctor has certain obligations to society, patients, and colleagues; a doctor must honor the medical profession; a doctor must have qualities such as sincerity, compassion and empathy, patience and modesty; a doctor must obtain the patient's informed consent and female consent; practical activity should be accompanied by continuous medical education.

In comparison with Western bioethics which places a strong emphasis on human rights, Islamic bioethics is based on the duty to preserve life, to seek all possible ways of treatment; and the rights (of God, society, and the individual) are reflected in bioethics as human dignity (Ihsan). Islam is open to scientific knowledge, as evidenced by the Quranic verses and traditions of the Prophet:

- "It is necessary to study, to seek knowledge no matter how far it may be, even as far as China»;

- "The ink of a scientist is more sacred than the blood of a martyr. The acquisition of knowledge is mandatory for every Muslim, regardless of whether they are male or female."

\* Say, "My Lord, increase my knowledge." (Taaha 20:114)

Islam requires the patient to behave rationally and seek appropriate treatment, and requires medical personnel to strictly fulfill their mission to protect and save lives:

- "And the one who saves this soul, as it were, will save all people from death (Quran 5: 32; translation by Valeria Porokhova).

Islamic medical ethics has become an important component in international ethical discussions and at the third world Congress in 1996 in San Francisco there was a section on "Islamic Bioethics", where Muslim scientists spoke. One of the well-known researchers in the field of Islamic bioethics whose works have received international recognition, is the Avicenna Prize winner in 2005, Professor Abdallah Daar. He made a significant contribution to the study of the complex issues of bioethics in Islam.

Among important events in the development of Islamic bioethics, there is the publication of a guide to international ethical principles, including biomedical research of human beings in the perspective of Islam, Geneva, 2004. The guide was prepared and published by the Council of International organizations of Medical Sciences (CIOMS) in collaboration with WHO and the Islamic

organization of Medical Sciences (IOMS) in Geneva in 2004.

The principles of professional ethics of a Muslim doctor stipulate that all human research should be conducted in accordance with three basic ethical principles: respect for the autonomy of the individual, generosity and legality. Each ethical principle is accompanied by comments from the Koran or principles and laws of Islamic jurisprudence, which confirm this principle. If representatives of vulnerable groups (minors, persons with impaired mental capabilities, the disabled, terminally ill, comatose patients, etc.) are invited to participate in the study, they should also be given the opportunity to choose whether to participate or not (to the possible extent). Their objections should not be ignored, and their rights should be carefully protected. Each group of these persons should be considered separately.

Respect for individuals includes obtaining informed consent to participate in the research from a third party (for example, a witness) in order to strengthen the protection of the rights of subjects. Consent to participate must be voluntary. It is unacceptable to use violence or undue pressure to obtain consent to participate in the research, especially for members of vulnerable populations. Here are a few comments from the Quran given in the Guide. The law of Islam calls for recognizing, preventing, and reducing harm.

"Any action that causes harm or hinders the benefit must be prohibited."

"Mandatory prevention of a greater evil when the lesser of two evils is chosen."

Ethical requirements are a prerequisite for research; they are part of the research management and the criterion of research quality, which should not become an obstacle. This condition requires new and additional qualities on the part of the researcher; it requires special education (bioethics, biomedicine) and training of researchers. Not everything that can be implemented in terms of scientific and technical capabilities can be resolved ethically. Currently, the social, legal, and economic aspects of key bioethical issues in the field of health, medicine, and biomedical technologies continue to be studied in the context of the Islamic faith.

Islamic bioethics is developing dynamically. It is not confined exclusively to the aspect of the creed, but integrates and transforms the most important international documents (the Nuremberg code, the Helsinki Declaration, the Universal Declaration on bioethics and human rights, etc.). Over the past 35 years, such issues of bioethics in Islam as organ and/or tissue transplantation, criteria for brain death, principles of care and technology in the intensive care unit, problems of reproductive technologies, cloning, genetic engineering biotechnologies, AIDS, psychiatric care, and etc. were put on the agenda and reviewed. International conferences were held by the Islamic Organization of Medicine (IOMS) in Kuwait, Istanbul, Karachi, Cairo, etc. Various key

issues of bioethics were considered; special attention was paid to children's rights, spiritual development and the moral component of medical educational programs in order to train a Muslim doctor.

Muslim legislators regularly meet to discuss ethical issues related to the progress of biomedical technologies: problems of organ and /or tissue transplantation were discussed at the third symposium on medical law (1987), at the fifth international conference of Islamic medicine in Cairo (1988), etc. Modern Muslim medicine and bioethics are developing within the framework of enlightened Islam and medical ethics. However, despite the current practice of Islamic bioethics, there are problems and contradictions, starting with the recognition or non-recognition of its status.

The position of a conservative part of Muslim scholars (for example, Omar Hasan Kasule) (Kasule. 2005. P 2-4) is that they justify the appearance of bioethics in the West, its concepts, theories, and principles not by the rapid development of biomedical technologies, but solely by secularization. Therefore, they believe that bioethics is neither a law that would represent a force for the government nor a moral force/conscience; it does not have the status of science. According to Omar Hasan Kasule, Islam views the problems of human research as purely legal issues; Sharia law provides adequate principles and guarantees because Islamic law (Sharia), unlike Western law, includes both law and morality in its essence. In Islam, actions are divided into mandatory, recommended, permitted, condemned, and forbidden. Under special circumstances, especially when it comes to life and death, even forbidden things can be allowed.

Islam's medicine is eclectic, choosing the best, modern, affordable medical technologies that are compatible with the spirit of Sharia and Islamic society. Lawyers search and find answers to solve the problems posed by modern life. Supporting concepts are intended to be combined with the Sharia guidelines so that Muslim patients can use modern medical methods and technologies for the benefit of their health without violating the principles of Islam. The syncretism of Eastern tradition is also expressed in the fact that many Muslims, including those who live in the secular states of Central Asia, seek to adhere to their religion in almost all spheres of life. They mention the name of Allah on a daily basis, live according to the instructions of the Koran, the instructions of the Prophet, and believe that their actions are counted, that they will be judged at the Last Judgment. Despite the fact that concessions are made for patients, many try to adhere to the Muslim lifestyle. Hence, deep understanding of Islamic bioethics by doctors can improve the quality of treatment for this significant population group, and is crucial.

Central Asian States are secular states, but they are home to believers of various faiths. Therefore, it is important to consider the socio-cultural realities



of national traditions, and to study their experience in making decisions on key issues of bioethics in the context of not only Muslims, but also other creeds. Bioethics today is a socially significant field of knowledge that develops standards of ethical and legal security for human well-being in the field of healthcare, medical science, and education.

**The concept of brain death.** In Muslim countries, the definition of brain death is strictly defined. Brain death means a complete and irreversible stop of brain activity (hemispheres and brain stem) with complete destruction of its cells. In case of brain death, artificial ventilation can support the life/activity of other organs.

**Ethical problems of reproductive technologies.**

The main ethical issue related to reproductive technologies is the status of the embryo; from which point of its development is it considered a person who has the right to protect his life and human dignity? The use of "extra embryos" in IVF selection, and in general the production of excess embryos that cannot be transferred to the uterine cavity, devalues the very concept of "life" and lowers the moral bar of our society. In Islam, it is considered necessary not to use donor sperm or eggs. Otherwise, there is a violation of both the pedigree and the genetic code of a particular family. Islamic theologians and legal scholars compare this problem with the issue of adoption. The Holy Quran prohibits adoption when adopted children take the surname of a foster father. "Address them by their fathers. This is fair to God. And if you do not know their fathers, call them your brothers in faith." (Qur'an, 33:5). The use of donor sperm and eggs is considered an unusual form of adultery, since it is unclear who is the true father or mother of the unborn child, and pedigrees are mixed. What is the ontological and moral status of the embryo? From what stage of the embryo's development should it be considered a human being? To what extent does it have human rights? In the bioethics literature, various answers are given to the question: from the moment of conception, when the uniqueness of the future human being in the genetic plan arose; from the 14th day, when the embryo is implanted in the uterus and when the germ cells themselves are allocated (the "primary strip"); after the 30th day, when the differentiation of the central nervous system begins; from 7-8 weeks, when the embryo begins to respond to stimuli; after 7 months, when the sucking reflex is formed and the fetus acquires the ability to live outside the mother's body.

The general view of the Muslim tradition on the status of the embryo is expressed in the fact that a full human life with its rights begins only after the completion of the "ensoulment", although there is some form of life before the soul enters the embryo. Based on the interpretation of approaches in the Quran and the Prophet's hadith, Muslim scholars agree that ensoulment occurs approximately about

120 days (4 lunar months plus 10 days) after conception. Quran (verse 2, 228) states that a divorced woman cannot remarry for 90 days, thus avoiding doubts about paternity. A widowed woman should wait for the same reason, 130 days, or 4 months and 10 days before getting married again. By setting the time frame from 90 to 130 days (from 3 months to 4 months and 10 days), Quran indirectly determines the period during which the embryo takes the form of a human. Based on these provisions of the Quran and based on the legend of the prophet Muhammad, according to which God breathed the soul into the fetus at 3 months and one week, Muslims conclude that "the fetus as a human person can actually be spoken of starting from the first week of the fourth month, i.e. on the hundredth day of pregnancy" (Ben Hamida 1992, P. 50).

Other scientists, perhaps a minority, believe that this happens after about 40 days. Muslim legal scholars have slightly different views on abortion. Abortion is allowed after implantation and before embryo ensoulment occurs, in cases that relate to legal or medical reasons. Acceptable reasons include rape. However, many Shiites and some Sunnis usually prohibit abortion at any stage after implantation, even before ensoulment, if the mother's life is in danger. Abortion after ensoulment is strictly prohibited by all reputable specialists, but the vast majority make an exception to preserve mother's life. In a dilemma where a choice must be made between preserving the life of the mother or the embryo, then the mother's life is preferred; it is treated as a root, and the embryo as a twig.

Professor of theology Abul Fadl Mohsin Ebrahim, , notes in his study "Abortion, birth control and surrogacy in an Islamic perspective", presents the diverse views on the issue of abortion and the status of the embryo in various schools of Islam. He points out that the most flexible position regarding abortion among various legal schools of Islam is in the Hanafi school. Here, before the fourth month of pregnancy, an abortion can be performed if the pregnancy threatens the mother's life. The Maliki position prohibits an abortion after implantation has occurred. Shafi'is support the ban, calling abortion a crime if the fertilized zygote is violated. The school of Hanbali, specifying the cause of abortion, considers abortion to be a sin. After ensoulment, in which the embryo is considered to have equal rights with the mother, the dilemma is solved by the general principle of Sharia: choosing the lesser of two evils. Without losing both lives, it is life that should be preferred - that is, the mother's life. Referring to the Quranic tradition (5:32) to protect the sanctity of life, Mohsin Ebrahim concludes that everyone has the right to be born, and the right to live as long as Allah allows. The right to live in Islam is absolute.

**Childbearing with the participation of medicine.**

There are various methods of artificial childbirth. Artificial insemination is inserting sperm directly

into the uterus. It is used when one of the spouses is sterile. According to Muslim law the use of this method is allowed only in the case that the sperm donor is the legal spouse.

In vitro fertilization and embryo transfer (for women with tubal obstruction), is fertilization performed outside the body; 48 hours after fertilization, an egg is formed and this embryo is implanted in the mother's uterus. Then the pregnancy proceeds as usual. According to Islam, in vitro fertilization is considered legal only if the sperm of a woman's husband is used.

What is said about artificial insemination, which method is allowed, and which is considered forbidden? To answer these questions, the head of the fatwa Department of the Department of Muslims of Uzbekistan, Homijon Ishmatbekov, took part in the second meeting of the fatwa Council of the Eurasian Islamic Union, held in Istanbul on December 16-17, 2017. The agenda of the meeting included issues related to artificial insemination and artificial insemination. The Department of Muslims of Uzbekistan published a fatwa "on artificial insemination".

The practice of artificial insemination leads to some moral, social and religious problems. In particular, opportunities are opening up for women who want to have a child without getting married; the number of children born out of wedlock will increase; there may be situations of mixing ancestry (origin), ignorance of who the child's mother is; trade in fertilized eggs or non-fertilized eggs and seed cells can become a source of income. Given the above, the office of Muslims of Uzbekistan announced this fatwa:

1. The use of artificial insemination is allowed only in extremely necessary cases for married couples in accordance with the Muslim tradition-*nikoh*.

2. During artificial insemination, when storing the semen of men and women who have been married in Sharia, all precautions must be taken to prevent mixing the semen of other people. This operation must be performed by a qualified doctor.

3. Artificial insemination is prohibited for couples who are not married in Sharia.

4. Muslims who care about maintaining the purity of their ancestry should not use prohibited methods of artificial insemination.

**Carrying someone else's child.** If a woman's ovaries are functioning normally, but she cannot bear a child, she can take one or more eggs to fertilize them in vitro with her husband's sperm. The resulting embryo is placed in the uterus of another woman after 48 hours, who gives birth to a child after 9 months. Since Islam recognizes polygamy, the gestating mother may be the second wife of the husband, who will give his sperm to fertilize the first wife's egg. However, Islam forbids this method of procreation if the egg does not belong to the wife of her husband or if the child is carried by an outside

woman. Thus, the Muslim religion allows only legal spouses to resort to artificial childbirth with the intervention of medicine and subject to the following conditions:

- it is necessary to know the donor of the germ cells in order to exclude incest and ensure legal kinship in accordance with Muslim law;

- mutual voluntary and conscious consent of the legal spouses is required.

**Prenatal diagnosis.** Great progress has been made in this area, which raises a number of legal and economic ethical issues. There is a question whether such diagnostics should be performed before in vitro fertilization in order to make sure that the embryo is of good quality. In this case, it is easy to slip into eugenics, which is condemned by the morals of all religions. The traditional method of prenatal diagnosis is cytogenetic analysis with the establishment of the embryo karyotype, carried out on cells taken during amniocentesis (at 14 or 15 weeks). Another method is biopsy of trophoblastic tissue of the chorionic villus through vagina that has the same genetic material as the embryo. It allows for prenatal diagnosis at 5 or 6 weeks. If the fetus is found to have a genetic abnormality, then one can consider a voluntary termination of pregnancy at 9 or 10 weeks, that is, in more favorable conditions.

**Organ and/or tissue transplantation.** From the point of view of the Muslim public, it is pointless to interfere with the actions of nature in relation to imminent death. If active medical intervention in the case of a patient with a severely damaged brain leads to further suffering of the patient and those associated with him in society (relatives or friends), the subsequent harm cannot be ignored. However, there is no reason in Islam to put an end to human life just because of the suffering of the family and the patient.

In Muslim culture, until recently, when modern medical technologies did not recognize the difference between the termination of brain and cardiorespiratory functions, the announcement of death was based on the criteria provided for the viability of the interconnected systems of the human body. The concepts of cerebral death and brain death are neologisms in Muslim society that perceive death as the termination of vital functions in a particular organ system, rather than a part of the body. Complete cessation of the heartbeat was considered a sufficient criterion to declare a person legally dead. The problem arose when modern medical technology acquired the ability to preserve life functions through respiratory support in the patient's brain stem. The patients were alive according to the traditional definition of death. Thus, another important issue of organ transplantation was raised.

A long discussion in the Muslim community continues to this day. In Iran, the current criteria for brain death based on the principle of non-harm were

rejected in 1995, but theologians who adhere to enlightened Islam believe that brain death is a sufficient criterion for recognizing a person as dead. This is also stated in the fatwa of the Muslim Law Council of Great Britain, which moves from the problem of brain death to the issues of transplantation:

"The Council concluded that if reliable doctors certify that the brain stem is dead, it means that the person is dead from the point of view of Islam and thus the organs needed to save the lives of others can be extracted and the life support system can be turned off." (Mohammed Ghaly, 2012).

The Islamic organization of medical Sciences (IOMS) discussed this issue at two symposia held in 1985 and 1996, respectively, and concluded that brain death is an acceptable criterion for death. The same view was adopted by the international Islamic Fiqh Academy (IIFA) at its third session, held in 1986. However, the Islamic Fiqh Academy (IFA), at its tenth session in 1987, did not recognize brain death as an adequate criterion for death in Islam.

Over the past 35 years, issues such as organ and tissue transplantation, brain death, the principle of care, and technologies in the intensive care unit have been put on the agenda of Islamic bioethics. The problems of organ and tissue transplantation were discussed by Islamic lawyers at the third symposium on medical law (April 1987). In Iran, the International Congress of Bioethics (March 2005) stated that decisions on key issues of bioethics should be made with a consideration of existing religious norms, morals, and cultural traditions. Organ transplantation, such as corneal transplantation of a deceased person, is permitted under the following conditions: death must be determined by three doctors, including one neurologist (the surgeon who will perform the transplant must not be part of this group); the deceased should not have objected to such an operation during his lifetime, or must have the consent of relatives; transplantation is performed in centers officially recognized by the Ministry of Health of the country concerned.

1) *Live donors*. Organs that can regenerate (kidney, bone marrow, liver) can be transplanted from a living donor. In these cases, Islam does not impose any restrictions. 2) *Dead donor*. In dead fetuses, only cases where organs are used for therapeutic purposes are recognized as legal. In dead adults, the main condition for stopping artificial respiration and blood circulation and then taking the organ for transplantation is a statement of brain death. The Council of Health Ministers of the Arab-Islamic countries adopted a draft law on human organ transplantation consisting of 11 articles. Transplantation of organs of the deceased person was allowed with the consent of the relatives of the deceased and provided that: the death was determined by three specialist doctors, including a neurologist, and the surgeon who will perform the operation should not be part of this group; the

deceased did not object to the removal of any organ of his body during his lifetime. It is forbidden to sell or buy any organ or make it an object of donation for any remuneration. Organ transplantation may be performed in medical centers officially recognized by the Ministry of Health (Ben Hamida, 1992. - P. 53).

## Conclusion

Currently, the social, legal, and economic aspects of key bioethics issues in the field of health, medicine, and biomedical technologies in the context of the Islamic faith continue to be studied. Islamic bioethics is developing dynamically. It is not confined exclusively to the aspect of the creed, but integrates and transforms the most important international documents (the Nuremberg code, the Helsinki Declaration, the Universal Declaration on bioethics and human rights, etc.).

Over the past 35 years, emerging issues of bioethics in Islam as organ and tissue transplantation, criteria for brain death, principles of care and technology in the intensive care unit, problems of reproductive technologies, cloning, genetic engineering biotechnologies, AIDS, psychiatric care, and etc. were considered in international conferences held by the Islamic Organization of Medicine (IOMS), and attention was paid to spiritual development and the moral component of medical educational programs in order to train a Muslim doctor. Modern Islamic medicine and bioethics are developing within the framework of enlightened Islam and medical ethics.

## Competing interests

All authors declare that they have no competing interests.

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is in the best interest of all humans to adopt human rights based universal ethical principles.

## Introduction

We live in an era where what is researched in Pretoria will be later studied in Boise. Long gone is research focused on just a national or regional audience that is free from world scrutiny. We are now in an information age whereby mere seconds separate the exchange of information around the world. Research that previously concentrated on a segment of the population in one nation, can expect to have its findings and study methodologies analyzed across the globe, especially if it is felt to not conform with “international standards”. Gone is the era where certain views depicting some humans as being subhuman allowed research to be conducted in the same manner than that conducted on animals (which has further spurred a debate on animal rights as well, but I digress). History has shown that if allowed, some humans will view certain members of their society as “less than” the other members, whether it be due to their religion, their race, the color of their skin, their status as prisoners, or their physical or mental handicaps. It is this relative mistreatment of individuals that the principle of universalism speaks against, and to which I will dedicate this paper.

To distinguish this work from the many others debating the virtues of one philosophy over the other, I would like to take a slightly different approach advocated by a handful of scholars in the research community. It seems that the debate between advocates of universalism and relativism in research have generally taken to extremes to defend one view and criticize the opposing (Tangwa, 2004). The pursuit of truth between opposing points of views or accounts, typically lies somewhere between both extremes. As it is commonly defined, universalism holds that morality is the same everywhere and that established ethical rules apply cross-culturally. Relativism holds that different cultures and customs give rise to divergent values and thus differing ethical principles.

The accepted principles of research include respect for persons, beneficence, and justice, which are equally universal in their scope of protection; however, it is my view that the principles of justice and respect for persons are most instructive to the need for universalism in research.

## Justice in research

The role of the principle of justice was most famously raised in clinical ethics by Beauchamp and Childress (2013) with their four principles: respect for autonomy, beneficence, nonmaleficence, and justice. Justice is specifically defined by them as “fairness in the distribution of benefits and risks” (Beauchamp and Childress, 2013), and generally as a principle of fair and equitable treatment of persons. Research ethics has similarly attempted to adopt the principles of justice as part of

## An ethical proposal for Universalism versus relativism in research

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### Abstract

This paper seeks to advocate for the adoption of universalism as the ethical basis for research principles versus relativism, which would allow for different rules for different cultures. I will argue that although borne in, and out of, Western ideologies, it

its tenets. The Belmont Report, created by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research by the US Congress in April 1979, “articulated respect for persons, beneficence, and justice as the broader ethical principles to provide a basis on which specific rules may be formulated, criticized, and interpreted” (Emanuel et al., 2008). Historically, justice “was considered largely in terms of ensuring that burdens of research were not unfairly carried by the vulnerable of society” (Killen, 2008), and “requires fairness in the distribution of both the burdens and the benefits of research” (Beauchamp, 2008). Additionally, “justice, addresses who ought to receive the benefits of research and bear its burdens. The principle of justice requires that there be fair procedures and outcomes in the selection of research subjects” (Porter and Koski, 2008). It seems that fairness, as I will equate justice to mean, does not follow the relativist argument. To be fair in selection (and treatment) is the very underpinning of what human rights-based universalists advocate for all peoples around the world irrespective of individual differing cultures.

Emanuel et al elucidated certain guidelines for research scientific validity, which I will surmise have a universal applicability and are not to be taken as solely an American or Western world rulebook, or conversely one which only applies to “X” culture but not to “Y” culture. Congruent to the point of universalism, the authors state “Unless research generates reliable and valid data that can be interpreted and used by the specified beneficiaries of the research, it will have no social value and participants may be exposed to risks for no benefits” (Emanuel et al., 2008). It is hard to imagine a morally intact researcher arguing against this point and/or suggesting that there is a relativist sentiment attached to this statement. In continuation of their position on scientific validity of research, they explicate the following four benchmarks:

1. The scientific and statistical design and methods of research must plausibly realize the objectives of the research and must also satisfy the generally accepted norms of research.
2. A research study must be designed to generate results that will be interpretable and useful in the context of the health problem
3. The study design must realize the research objectives while neither denying healthcare services that participants are otherwise entitled to nor requiring services that are not feasible to deliver in the context
4. Finally, the study must be designed in a way that is practically feasible given the social, political, and cultural environment in which it is being conducted.

I believe most researchers, academics, and ethicists will agree with the first two benchmarks with little fanfare or argument and I will withhold further analyses of these principles. However, the third benchmark requires some further analysis, as it is the subject of frequent criticism by those who feel researchers have certain obligations to research subjects who do not have access to certain levels of healthcare services available in wealthier areas. The fourth benchmark will be addressed in the ‘universalism vs relativism’ section.

It should come as no surprise, and it does not require extensive analysis and argument to accept that there are resource rich and resource poor areas in the world. I also would like to argue that there is benefit of research on healthcare issues affecting all populations whether they be rich and poor. I further argue that it is not necessarily the role of researchers to provide the resources for the poor areas in order to conduct responsible research in those areas. Nonetheless, researchers can (and should) follow universal rules of conduct for responsible research, despite a relative lack in resource entitlements from the host to the sponsoring nations. Clearly, the complete exposition of this argument goes beyond the scope of this paper but suffice it to say that the arguments from both sides of this debate are widespread and sometimes contentious. Emanuel et al. highlight the issue of healthcare service entitlements that research participants are afforded. They maintain that “studies can be ethically designed yet not provide a service or intervention individuals are entitled to under certain, restrictive conditions” for example placebos in treatments and/or diagnostics under certain acceptable rules of their use<sup>1</sup> (Emanuel et al., 2008). Their argument continues stating that the issue of healthcare service entitlements is complicated not only on a global scale (comparing resource rich vs resource poor nations), but even within wealthy nations. They state: “Even in wealthy countries, participants are not entitled to every available or effective medical service, because justice necessitates establishing priorities for the distribution of scarce resources” (Emanuel et al., 2008). To point out the obvious; justice is fairness and equity, but it is not equality. As reality mandates, no matter how rich a society may be, there is limited availability of scarce resources, of which healthcare services is amongst. Hence, the entitlement of healthcare services is subject to the just distribution of such scarce resources, which I maintain is a universal principle, i.e. it applies to all cultures and all peoples, and any system that attempts to put relative weight or preference on some peoples over the other is by definition unjust.

These arguments are presented to suggest that although there might be cultural variabilities

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<sup>1</sup> There is a methodologically compelling reason to do so, and there is only minimal chance of serious harm, such as suffering irreversible morbidity or disability, or reversible but serious injury.

between different nations where research is conducted and sponsored, an adherence to the same principles of responsible conduct of research need not obviate universal rules of research. Conversely, a relativist principle would suggest that rules in certain nations could be limited to the local guidelines, which may not align with internationally recognized rules of research. This has been repeatedly shown historically to be fraught with opportunities to take advantage of vulnerable populations and violate the principle of justice in fair selection and equitable distribution as previously described.

### **International research events and guidelines (respect for persons)**

I believe it will be instructive to present some of the foundations of research ethics and the principles put forth by the world's largest research sponsoring and regulating agencies. Although many authors have argued that international research guidelines are mostly in response to past (mostly developed world) atrocities, they are still the guide through which responsible research is viewed (Emanuel et al., 2008). Beauchamp (2008) states that the respect for persons "demands that the choices of autonomous persons not be overridden or otherwise disrespected and that persons who are not adequately autonomous be protected by the consent of an authorized third party likely to appreciate their circumstances and who will look after their best interests". Within this principle is the need for voluntariness and informed consent.

In the United States, the National Institute of Health (NIH) put forth seven principles to guide the conduct of responsible research. Namely,

- Social and clinical value
- Scientific validity
- Fair subject selection
- Favorable risk-benefit ratio
- Independent review
- Informed consent
- Respect for potential and enrolled subjects. (NIH, 2016)

Arguably, these principles themselves are derived (at least in part) from recommendations from the Nuremberg Trials and the resultant 10 principles that comprise the Nuremberg Code (Annas and Grodin, 2008). The trials were conducted in response to the Nazi atrocities of World War II (WWII), and provided guidance on the responsible conduct of research for the world stage. Other globally recognized research guidelines, such as the Belmont report was a response to the Tuskegee Syphilis Study, whereas the ethical guidelines of the Advisory Committee on Human Radiation Experiments were a response to radiation experiments conducted in the US (Emanuel et al., 2008). The World Medical Association (WMA) adopted the Declaration of Helsinki (DoH), and recently updated it in response to the "controversy surrounding placebo-controlled trials in developing

countries" (Emanuel et al., 2008). Interestingly, the power and international reach of the DoH was succinctly described by Capron (2008) as follows:

*"The evolution of the Declaration—which has become much longer and more detailed, and which now takes into account interests beyond those of practicing physicians—reflects the reality that in many parts of the world, this document, produced by a professional association, provides the de facto legal criteria for consent and other ethical requirements in research. Indeed, the U.S. Food and Drug Administration (FDA), which in 1975 first incorporated the original Declaration into its regulations for foreign clinical trials conducted without an investigational new drug application (IND), still relies on the Declaration's 1989 version as the standard to which investigators are held."*

Although it is far from a perfect document, the DoH has as its greatest strength its universality and clarity for researchers around the world "wishing to avoid unethical practice and by ethical committees wishing to enforce ethical standards" (Aschcroft, 2008).

Given the Western/American origins of many international research guidelines and regulations, these rules for research have been viewed by some as an "imperialistic" and Western attempt at globalizing their views and mores on developing world nations and eliminating (or at least jeopardizing) the local cultures. There may be some truth to that; however, I believe the internet has a much further reach and effect than international research guidelines. This notwithstanding, the "common rules" for research, "focused primarily on the processes of review, approval, and oversight of research with humans generally" (Porter and Koski, 2008), are supported by most agencies within the US federal government as well as the research regulations of the US FDA. And as previously mentioned, it finds in its origins many of the principles of the earlier versions of the DoH. As a result, international studies sponsored or conducted by American biotech and pharmaceutical companies can further extend the global influence of the Common Rules due to the need to submit their research findings to the FDA for final approval and licensing (Emanuel et al., 2008).

Given the international scope of scientific research, and its impact on all humans, its moral code must succinctly address and protect the moral code and interests of all humans. Merton (1973) stated, scientific research must be universal, and should not depend on who or from where it comes from. Merton (1973) further exemplifies scientific research based on relativist principles that have led to a "moral strain" and have even "hindered the advancement of society". Clearly, the atrocities of Nazi Germany, among many other regional crimes of research, come to mind regarding some of the pitfalls of a relativist scientific ethic. An argument frequently levied against relativists in their culturally based ethics principles is the Nazi

Germany era. Many of these experiments were conducted under and even scrutinized by the research ethics of the Third Reich. They were said to be conducted under the strictest conditions of “proper scientific research” (Annas and Grodin, 2008). Similarly during the early 1900s, research was conducted by the Japanese under a similar view that the Chinese (and other imprisoned non-Japanese) were subhuman and did not violate their established local rules and ethical research guidelines for (Japanese) humans (Tsuchiya, 2008). These are just some of the many human rights abuses that have been committed in the name of research, with a common theme of them all being approved under local cultural guidelines. Ironically, this is why an international declaration of human rights was adopted (coinciding with the creation of the United Nations) after WWII to address the inconsistent treatment of all humans all over the world via the Universal Declaration of Human Rights (UDHR), which was accepted across nations globally (Johnson and Symonides, 1998).

Another case that highlights the need for universalism in clinical research, was the 1996 Pfizer clinical trial of the antibiotic Trovafloxacin during a meningitis outbreak in Kano, Nigeria. The outbreak, which affected primarily children, attracted the attention of local, national, and regional governments, as well as several international non-governmental organizations (NGOs) such as Medecins San Frontiere (MSF). Many have argued that the study violated many universal research ethics, namely respect for persons, need for informed consent, fair selection of subjects, and maintaining of a favorable risk-benefit ratio in the treatment modalities. (Okonta, 2014; Marchat et al., 2002; Wise, 2001). The principle argument behind these claims is that a Western corporation took advantage of a society that insulated itself from international rules, and conducted locally acceptable research on a vulnerable and marginalized segment of society similar to experiments conducted during the Nazi atrocities of WWII, which similarly violated the DoH and other internationally accepted research guidelines.

For the above stated reasons which have detailed the importance of the scientific method and the worldwide implications of its findings, it should not matter in what subdiscipline the scientific research occurs (i.e. basic research versus research involving animals, basic research versus research involving human participants). It is the need to respect all humans, regardless of where they reside, that supports my argument for universalist-based research. It is only through the respect and adherence to universalist principles that research conducted around the world can be ensured to be responsible. However, there are clearly some cultural differences around the world regarding the particular use of certain animals that should be respected. Nonetheless, the use of animals for scientific research should follow universalism.

### Universalism vs relativism

The previous examples of local cultures overriding international laws and human rights abuses, might be decried by relativists as imperialistic judging or meddling in local affairs by Western agencies. Relativists argue that individual cultures are better apt at establishing the ethics of human behavior. However, it is unfathomable that a relativist would not see any commonality whatsoever in any peoples of differing cultures. One could say, perhaps such basic commonalities between all humans is not sufficient to override the clear cultural differences, but I would argue that the commonalities, albeit few, are what is needed to be human. I would further argue that within each culture there are certain sets of guiding rules and principles that share things in common even with their most ardent enemy cultures.

As I alluded to in the beginning of this paper, the truth (or best approach) lies usually in between the opposing presented arguments. Msoroka and Amundsen (2018) similarly embrace “the application of universal ethical principles with diversity that permits partial detour from universal principles.” They further state that “Radical cultural relativism would hold that culture is the sole source of the validity of a moral right or rule. Radical universalism would hold that culture is irrelevant to the validity of moral rights and rules, which are universally valid” (Msoroka and Amundsen, 2018; Chandler and Munday, 2016). One of the concerns raised about universalisms is that it neglects to acknowledge local cultural mores. I reject this argument and join a chorus of other authors (ironically mostly Western educated with ties to the developing world like myself) who state we must distinguish relativism from absolutism. Tangwa (2004) likens our need for flexibility in moral rules to those of universalism. On the former, he says although moral norms and rules can be generalizable or “universalizable”, *“Moral norms/rules may, of course, be expressed in, mixed with, or reflected in laws, societal customs, cultural practices, taboos, etiquette, and so on. But all these differ from moral norms/rules proper in that they are—by their very nature and raison d’etre—context bound. A law, for instance, has no jurisdiction and no applicability outside of its area of sovereignty. Moral precepts are necessarily universal as well as abstract and, if their dynamic and dialectical relation with concrete particulars is not properly appreciated, they may appear rather empty.”*

It is my understanding of Tangwa that although moral principles can be derived from a universal source, they may require contextualization in the local culture to which they are being applied. This does not in and of itself eliminate the universal ethic that was originally applied, but only provides “local flavor”, so to speak. He gives the classic Kantian example regarding a deranged murderer seeking a particular victim who runs by a 3<sup>rd</sup> party witness

asking if the intended victim has been seen. The absoluteness to which the moral rule of never lying would in most people's opinions clearly be inappropriate under such circumstances. Hence, the moral rule, can have exceptions and contextual variations. Again, this does not eliminate the universality of the underlying moral principle, in this case, lying is generally immoral. To insist on universalism to the extreme is to embrace absolutism. Tangwa (2004) continues his argument with the following:

*"The same point can be made by drawing a distinction between universalism and absolutism. Moral rules are universal but not absolute: they can admit justifiable exceptions. Such putative exceptions, however, do not justify the postmodernist relativistic position that moral judgments are or ought to be entirely culture bound or culture dependent. In other words, accepting the possibility of a justifiable exception to the applicability of a moral rule in no way implies moral relativity, let alone the absurd idea of "geographical morality" or ethics which change at territorial borders. Obeying or applying an ethical rule, however, is necessarily done within the constraints of the particular place, time, circumstances, and perspective. To say that there are ethical universals—that is, norms and values having cross cultural validity—is to make an understatement. It would be more accurate to say that all ethical norms or rules are cultural universals, because a rule or norm cannot properly be described as "ethical" unless it is understood as having cross cultural validity, in the sense of being perceived as applying in all similar circumstances, irrespective of place and time."*

Again, exceptions must exist for every rule in order for them to be universal, and such exceptions do not make them necessarily culturally relativistic.

## Conclusion

In order to ethically conduct research, we as a society should expect researchers to respect the rights of the individuals who have volunteered knowing the reasonable risks and consequences of their participation. To do so is not just a Western ideal, but an expectation all member states of the UN have agreed to (Johnson and Symonides, 1998). To allow cultural variances that do not conform with or respect universal ethical principles is to open up a door for potential human rights abuses that have dominated research (and humanity) since its inception. Universalism with a degree of flexibility is the appropriate manner in which to conduct research in cultures with particular elements that may require a different approach to the research subject.

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## Fostering integrity in scientific research: understanding conflict of interests (COI) through responsible conduct of research (RCR)

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### Abstract

A conflict of interest situation can potentially harm the integrity of research and contribute to research misconduct. This study highlights participants' perception and knowledge on issues related to conflict of interest. In response to mails to 40 participants in RCR training, 15 of them agreed to the interview. The interviews demonstrated that the participants' knowledge regarding conflict of interest in research was rather limited and particularly focused on the financial aspect of conflict of interest. Participants stated that the training program had increased their knowledge on the different types of conflict of interest and also provided them the necessary knowledge on how to manage conflict of interest in their research. However, since this is an incidental finding, the necessary method of handling different types of conflict of interest was not immediately instigated during this study as it was not the focus of the interview at the time. Conclusively, there should be a need to expose the researcher to issues related to conflict of interest. Considering the variation of conflict of interest policies by research institution, academic journals and funding agencies, they might not be adequate to maintain a high level of research integrity.

### Introduction

The importance of responsible conduct of research or RCR's training program has been the focus of the

scientific community for the past three decades. It is a phrase that is used to describe several concepts associated with the discovery and discussion of newfound knowledge including topics on research, responsible science, scientific integrity and responsible researchers (Horner & Minifie, 2011). The training in RCR has become necessary for some research institutions including the National Institutes of Health (NIH) and National Science Foundation (NSF) which made it compulsory for their funded research trainees to have RCR training. Since then, responsible conduct of research (RCR) training has become one of the requirements for PhD students as well as for postdoctoral training, particularly in biomedical sciences (McCormack & Garvan, 2014). Initially, there are nine core areas in the RCR training program including data acquisition, management, sharing and ownership; mentor/trainee responsibilities; publication practices and responsible authorship; peer review; collaborative science; human subjects; research involving animals; research misconduct; and conflict of interest and commitment (Schamling & Blume, 2009). However, there might be some variability in the training program, depending on the trainees' discipline.

Even though the definition, types and handling of conflicts of interest and commitment is specifically mentioned on the website of Office of Research Integrity (ORI), there has been no consensus on the definition of conflict of interest. For some, conflict of interest (COI) is a situation where an investigator is tempted "to compromise professional judgment for financial or personal gain" (Thompson, 1993; Werhane & Doering, 1997). Conflict of interest could happen when an individual or an institution has a primary allegiance that requires certain actions, and at the same time, has a secondary interest that could jeopardize their primary allegiance (Cohen, 2001). Therefore, this interest may result with the individual or institution failing to perform their primary ethical or legal obligations to research subjects, colleagues, research institutions, or the public (Thompson, 1993; Shamoo & Resnik, 2003). However, according to most researchers or institution, some conflicts of interest are unavoidable which can vary in term of significance, as there is a natural tendency to create preconceptions and biases as well as the possibility to influence the investigator's thinking and behavior; this emphasizes the need to manage the conflicts appropriately and transparently (Coyne, 2005). On the contrary, conflict of commitment refers to any conflict between two sets of professional obligations that could both be adequately fulfilled without compromising one's judgment in fulfilling either of them (Werhane & Doering, 1997).

Mentioning a conflict of interest is normally associated with the financial aspect of research but individuals may also have many other interests that can affect their judgment, including personal, professional, political, and intellectual interests. For example, Sollitto et al (2003) highlighted that

although some investigators may not have any financial conflict of interest in a clinical trial, they may have strong interest in conducting and publishing the outcome of the research outcomes. At the same time, the research institutes including universities, medical schools, or hospitals can also have a conflict of interest, in which the institution has a financial or other interest that tends to affect its decision-making. It may result in their inability to fulfill their primary ethical or legal obligations to the research subjects, profession as well as the public (Shamoo & Resnik, 2003).

Conflicts of interest are important ethical problems for scientific research for at least three reasons. The first reason is that it can influence the outcome of research as there is considerable evidence showing a connection between the source of research funding and the outcome of biomedical research studies (Krimsky, 2003). This connection was found in studies by Friedberg (1999) and Stelfox et al (1998) where they found that more than 90% of publications sponsored by pharmaceutical companies favor the company's products. This is because pharmaceutical companies who funded the research can withhold research results that showed negative outcomes which caused biased interpretations of the data (Krimsky, 2003). Secondly, conflicts of interest can harm patients because investigators who have conflict of interest may be tempted to bend the rules and engage in unethical research practices while conducting research in order to produce desirable outcomes. Finally, for the third reason, conflicts of interest can also reduce the trust that public have in the research enterprise because research subjects, politicians and lay people may view investigators with COIs as biased or unethical (DeAngelis, 2000; Shamoo & Resnik, 2003).

An article by Horner & Minifie (2011) provides empirical support for the influence of outside interests on investigators and authors. Several articles have examined the relationship between conflicts of interest and research results (Friedman & Ritcher, 2004; Kelly et al, 2006; Kjaergard & Als-Nielsen, 2002; Perlis et al, 2005). While some literature examined conflicts of interest policies (McCrary et al, 2000; Studdert, mello & Brennan, 2004; DeAngelis, Fontanarosa & Flanagan, 2001; Stossel, 2005; Sharp & Yarborough, 2006), others examined the influence of industry on research outcomes from the perspective of potential research participants (Kim, Millard, Nisbet, Cox & Caine, 2004; Wienfurt et al, 2008) and readers of the scientific literature (Schroter, Morris, Chaudhry, Smith and Barrat, 2004).

An "uneasy alliances" was reported between clinical investigators and the pharmaceutical industry, where the strong influence of the pharmaceutical industry over trial design, data analysis, decisions about what to publish and when, and the use of professional ghostwriters as authors were highlighted (Bodenheimer, 2000). However, a

study by Buchkowsky and Jewesson (2004) on 500 pharmaceutical trials showed that the outcome from the studied drug is no different from publicly funded trials. Whether the drug trials were funded by a private pharmaceutical company or governmental organizations, the outcomes were still favorable to the studied drug. This finding contradicted with the forgoing studies that found a greater likelihood of favorable outcomes for industry funded trials (Lexchin, Beres, Djulbegovic & Clark, 2003).

In addition, there is variability in terms of policies on conflict of interest, including variability across different institutions, vagueness of definitions, lacking of procedures in terms of managing conflicts of interest, and also lacking accountability for those who breach ethical conduct. What makes the matter worst is that, despite the requirement to have policy on conflict of interest, there are still quite a number of institutions that do not have one. In general, conflicts of interest or commitments do have the potential to influence research outcomes and publication practices. Thus, some suggest that disclosing the conflict of interest is sufficient but others suggest that both individuals and institutions should be subject to tighter regulations to assure uniformity in order to maintain researcher subjects' trust in the research ecosystem and subsequently, to assure scientific records are reported with high integrity.

There has been an increase in research done by Malaysian researchers in local research institutions including public and private universities to support the government's aim to place the country researchers on par with other high impact researchers in developed countries (NST, 2018). Some of these researches are collaborative research between universities and industry players; therefore, they create tendencies for conflict of interests between both parties. Most previous studies on COIs are related to financial conflicts between research institutes or investigators and funders of research (McCrary et al, 2006; Bekelman, Li & Gross, 2003; Friedman & Ritcher, 2004; Rockey & Collins, 2010; Cooper, Gupta, Wilkes & Hoffman, 2005; Blumenthal, 2002; Dunn et al., 2016; Bero, 2017), particularly in the field of biomedical sciences. However, there are other aspects of conflict of interest that are seldom discussed in the literature. Hence, it raises a question regarding researchers' knowledge on issues related to conflict of interest. Currently, most institutes of higher learning in Malaysia have conflict of interest procedures or policies but information on researcher's knowledge regarding the types of conflict of interest is still limited. Therefore, the objective of this paper is to explore participant's knowledge and views on conflict of interest and to highlight the importance of RCR training with regard to strengthening researcher's awareness and knowledge about conflicts of interest. Nevertheless, it is important to caution that the findings in this study cannot be generalized as it is based on the views of selected researchers.

## Methodology

A qualitative method was used for this study because it is well suited to the needs of the study, that is to explore participants' views regarding conflict of interest. In response to a mailing of 40 participants of RCR training, 15 participants agreed for an interview over a period of six months. In-depth interview is an appropriate approach for a wide range of topics, particularly when investigator intends to explore, and highlight participant's opinion and perceptions on the topic discussed.

*Participants:* Universiti Kebangsaan Malaysia approved this study. Participants were recruited from mid-April 2018 to end-October 2018. The participants in the study were either those who had participated in the jointly organized Young Scientist Network-Academy of Science Malaysia (YSN-ASM) and High Education Leadership Academy (AKEPT), or those who had attended RCR training organized by trainer or RCR training by YSN-ASM and AKEPT.

Recruitment of participants for this study was from a wide range of academic disciplines including physical sciences (4), medicine and health sciences (6), engineering (3), pharmacy (1), and science and technology (1), and consisted of six male and nine female participants. Most of the respondents were early career researchers with less than five years research experience, while some had more than 10 years' experience in research. Eleven respondents were from research universities (RUs), while four were from non-RU. The answers to these questions highlight their knowledge and view on conflict of interest. It may also highlight some suggestions raised by participants on improving researcher's knowledge regarding conflict of interest.

*Data collection:* Data were collected via in-depth interviews. The design of the open-ended semi-structure questionnaires was adapted and adopted from a previous study on plagiarism by Devlin and Gray (2007). It was modified and pilot tested. Prior to the interview, an email was sent to the participants including a brief introduction to the research and its purposes, why they were chosen to participate and an informed consent form. After participants provided us with their consent to the interview, time and venue was decided. The interview was conducted in English, and lasted between 45 minutes to an hour. The interviews were recorded and all of the interviews were transcribed.

*Data analysis:* Data was analyzed using thematic analysis and the analysis was validated with another researcher to compare and define the major findings to test their validity.

## Results

*Knowledge:* Our findings showed that participant's knowledge regarding conflict of interest is still very limited. Although they had heard and dealt with the term all the time, they were not aware of the depth

of issues related to conflict of interest. Most participants' knowledge on COIs were restricted to financial conflict of interest and this is not surprising because most of them are from the biomedical field, where they are sometimes involved in collaborative research with medical or pharmaceutical companies. One participant said: *"I realized how little I know about COI. When I wrote the paper, you know that you need to make declaration right. It's like automatic you write no conflict of interest. For me being in the medical science field, I would only think about the conflict in term of finance or collaboration. But in this training program, they also talked about COI in term of publication, peer review or even grant proposal. That is something new for me."*

Issues related to COIs are seldom discussed in ethics education so that some took it for granted and did not view the issues as anything serious: *"I seldom really think seriously about conflicts of interest. I mean you thought that you know it good enough but when we discussed it in detail and thoroughly, I realized wow, there is so much detail on COIs that I do not have knowledge about. It is only after the session that I think about conflict of interest thoroughly when I do research and publication. So, yes it really is an eye opener."*

Another participant said: *"Basically I heard about COI and basically I know what it is but only after the workshop when it was presented and discussed in detail that I get to learn more and in depth on issues related to COIs."*

*Personal relationship:* According to Werhane and Doering (1997), conflicting interests may involve commercial or financial interests, reputational interests, or simply conflicting commitment of time, expertise, energy or interest. However, some researcher may not be aware of different types of COI. For instance, one of the participants mentioned that she didn't know that certain actions are considered to be a conflicting interest: *"I did not even know that when you are one of the reviewers for grant proposal and you found out that the grant applicant is someone you know personally, and yet you still forgo with the review. And that actually is a conflict of interest. That I am not aware of."* [P5]

In addition, two participants shared their opinions: *"I am not aware that having both husband and wife in a research team is considered as conflict of interest. It never occurred to me that it can lead to COI."*

*"You know, COI was the most debated topic during the workshop, which is mostly based on the personal experience of other participants. For example, in peer review for publication, I just knew after the workshop that it is a COI when you do review for someone whom you know come from the same department or using the same laboratory as you. It is like you have a 'personal' relationship with them."*

*Financial management:* A participant believed that lack of knowledge in financial management also can lead to conflict of interest: *"We normally learn about*

*financial management through our own experience or we learn from our supervisor. Yes, as student we did apply for grant but the financial part is normally handled by the supervisor. So, when you are now researcher, I didn't know that applying for grant can also cause COI. I thought that COI can only happen during collaboration or publication."*

*Hierarchy: Holding a certain position within the faculty or research team, or being appointed to that position sometimes can lead to a situation where it indirectly creates a conflict of interest: "It opened my eye on the different types of conflict of interest. You know sometimes you are either appointed or got certain position that you might have the ability to abuse. It's like you have the opportunity to abuse it for your own good. At the same time, I also learned how to handle it."*

#### *Handling strategies of COI:*

The training program also taught participant how to handle different types of conflict of interest. This was agreed by a participant where he mentioned: *"I think I learned the most in term of COI. Not only have I learned about the different types of COI but also how to handle different types of COI."*

However, unfortunately further details on different methods of handling COIs were not asked during the interview. Therefore, it is suggested that future studies on the topic of COI and RCR training should include strategies of handling COIs. Overall, the findings showed that the workshop managed to increase participants' knowledge and awareness regarding different types of conflict of interest and how to handle different situation of COIs. Although the data might be minimal in term of the number of participants, it provided an insight on how we need to educate researchers with knowledge regarding conflict of interest as a lack of knowledge in COI can potentially lead to research misconduct. At the same time, it also highlighted the importance of research institutes investing in RCR training program in order to provide researchers with a platform for discussion on other ethical aspects of research including COIs.

## **Discussion**

We could not find any other study that explore researcher understanding and knowledge regarding issues of conflict of interest in Malaysian university, therefore, indicate the significant of this study in order to know how far do Malaysian researcher cum lecturer know about conflict of interest. Our findings showed that participants are very intrigued in the topic related to conflict of interest because thorough discussion on the topic are rarely done in any ethics classes or subject that they had attended previously. The growing interest in COI is not new particularly among biomedical research (McCrary et al, 2006) due to the realization that commercial interests play a strong influence on the researchers, reviewers as well as the editors, during the peer-review process. Therefore, making COI a sensitive and of utmost

importance issues to the field of biomedical research (Friedman & Ritcher, 2004). In fact, the discussion among other researchers during the RCR training, particularly regarding their own experience with conflict of interest has become an eye-opener for them and they realized that there are other different types of conflicts of interest and different way of handling it. According to Weinfurt et al (2006), discussions on COI has subsequently raised concerns about both the integrity of clinical research and protecting the right and welfare of research participants (Weinfurt et al, 2006).

Our findings highlighted the lack of awareness of participants on the different types and situations related to conflict of interest. According to Horner & Minifie (2011), there are generally three types of conflict in academic research: commercial or financial competing or conflicting interests, conflict of commitment, and conflict of guidelines. The clearest and most often discussed example of a conflict of interest in biomedical research involves doing research on a specific intervention while receiving research funding or personal remuneration from the company producing the intervention. While there are many other forms of financial and non-financial conflicts of interest (Horton, 1997), this is the type that is most often measured and discussed (Dunn, Coiera, Mandl & Bourgeois, 2016).

Previous researches on COI have focused primarily on issues related to financial conflicts of authors, which is also evident in our study. Yet, non-financial interests can be equally important, because it can affect the whole process of publishing the research findings in academic journals (Bird & Spier, 2005; Levinsky, 2002; WAME, 2006; Smith, 1998). Non-financial conflicts of interest can occur during publication, particularly when the author has a professional or personal relationship that could influence or bias his or her decisions, interpretations, conclusions or publications (Ancker & Flanagin, 2007). There is also a growing concern on the influence of social context in which the research was conducted, on the outcome of the research results (Bero & Grundy, 2016).

Conflict of interest is more common than most of us realize and it is commonly unreported because researchers are not aware of the different types of COI. This was also found in our study where most of the participants came to realize how common conflict of interest was in their daily conduct of work once they knew the different types of conflict of interest. When they did not realize that such situation was a conflict of interest, they did not disclose it or report it. This concurred with a previous study by Bekelman et al (2003), where a third of biomedical researchers held conflicts of interest that could potentially introduce a risk of research or publication bias. Cross-sectional studies across a heterogeneous set of conditions suggest that in between 29% and 69% of published clinical trial reports, there are still quite a number of conflict

of interests that go unreported including disclosures of conflict of interest (Roseman et al., 2011; Roseman et al., 2012; Jagsi et al., 2009; Perlis et al., 2005; Matsen, Jette & Neradilek, 2013; Bosch et al., 2013; Bridoux et al., 2014).

A few other studies that measured undisclosed conflicts of interest, suggest that between 43% and 69% of studies fail to include disclosures of conflict of interest (Kesselheim et al., 2012; Rasmussen et al., 2014; Norris et al., 2012; Chimonas, Frosch & Rothman, 2010). This concurred with a cross-sectional study of published clinical practice guidelines issued by medical organizations in the USA and Canada, in which 48% of authors disclosed a conflict of interest, whereas approximately 25% of authors formally declared none; However, 11% out of the 25% were found to have an undisclosed conflict of interest (Neuman, KORENSTEIN, Ross & Keyhani, 2011). In a study on the Danish clinical practice guidelines, 96% of guidelines included at least one author with a conflict of interest, but only 2% of the guidelines disclosed those conflicts of interest (Bindslev, Schroll, Gøtzsche & Lundh, 2013). Most of these studies were conducted among biomedical or medical researchers, and we found very limited survey conducted among researchers from other fields. One of the reasons given is that medical science already has a well-established and written policy on conflict of interest, and it is suggested that future studies regarding COI should include researchers from other research fields, for instance, social sciences.

Researchers' knowledge associated with conflict of interest is rather limited. This was highlighted by one of the participants in this study, where she mentioned that her knowledge on the types of COI and how to manage COI was very limited before she attended the RCR training program. Thus, the need to provide researchers with more exposure and discussion on issues related to COI is highlighted so that they can identify and manage COI. However, Bero and Grundy (2016) mentioned that confusing 'interests' and lack of knowledge on 'conflict of interest' makes conflicts of interest appear so pervasive that they cannot be avoided but only disclosed. However, there are precedents for disclosing and managing financial conflicts of interest, which should be adopted and enforced widely within biomedical research institutions as well as other research fields. In fact, disclosing financial interests was highlighted as one of the strategies to manage COI or complete prohibition from research on a product in which one has an equity interest. This approach is often taken by institutions and regulatory bodies and also was recommended by expert panels in term of managing COI (Romain, 2015; AAMC, 2008; IOM, 2009; Drazen et al., 2009).

Curzer & Santillanes (2012), have suggested different approaches to manage COIs on different levels: professional, institutional and personal. One of the approaches suggested is to restructure the

profession in a way that it is able to eliminate or reduce various sorts of perverse incentives. Another suggestion is to regulate the researchers where they are urged to eliminate conflict of interest whenever possible, to minimize, monitor and disclose conflict of interest when necessary, and try to screen out immoral applicants from graduate programs. It was also suggested that researchers should attend compulsory courses or classes in research ethics before conducting any research so that they could be good mentors to their junior researchers.

Conflict of interest threatens all aspects of research process, from the choice of research problem, to research design, to recruitment and treatment of research subjects, to data interpretation, to peer-review of publication and grant applications (Curzer & Santillanes, 2012). Researchers with conflicts of interests will most likely prefer to choose comparators that would produce results, which are favorable to them (Lathyris, Patsopoulos, Salanti & Ioannidis, 2010), selectively publish outcomes that are significant (Mathieu et al, 2009), only publish conclusions that are consistent with the study results (Als-Nielsen, Chen, Glud & Kjærgard, 2003; Yank, Rennie & Bero, 2007), or complete a clinical trial but not publish the result (Dunn, Coiera, Mandl & Bourgeois, 2016). Based on these, it is concluded that conflict of interest can pose three general risks. The first risk is that conflict of interest can be a distraction to the researchers' observations and deductions of research thus undermining their scientific objectivity through bias. The second risk is that it may compromise the ability of researchers to decide what their duties are which can lead to the wrong action through warped moral judgment. Finally, the third risk is that researchers tend to engage in unethical action because of their weak will (Krimsky, 2003; Thompson, 1993; Resnik, 2006).

We would like to highlight that the lack of knowledge and awareness of participants in this study regarding issues related to conflicts of interest is an incidental finding. This finding, although incidental, shows that there is an urgent need to provide researchers with necessary knowledge on conflict of interest in order for them to identify and manage the issues at their institute. Therefore, emphasizing the importance of RCR training program for researchers in research institutions in Malaysia is highly recommended. Even though some researchers may have attended ethics education, discussion on topics related to conflict of interest is limited to the most common aspects such as financial matters. Mandatory education in research ethics may provide only a small impact to researchers' behavior but such training or education may improve and raise awareness on moral reasoning including issues on conflict of interest.

## Conclusion

Based on our findings, participants had limited knowledge on issues related to conflict of interest.

Most of them were aware of the financial aspect of COI but unaware of COI that involved personal relationship between researchers, which can potentially become a threat to the integrity of research. We also found that participants gained knowledge regarding the different types of COI and how to manage and handle it accordingly through their participation in responsible conduct of research (RCR) training program. Even though some of them might have attended ethics education before, the focus on COI was quite limited. In conclusion, our findings highlight the need for further study to investigate and explore researchers' knowledge and awareness regarding conflicts of interest in academic research, particularly on the different types of conflict and how to handle the situation professionally.

There is a necessary need to also focus on the topic of conflict of interest in research ethics education by providing researchers with different scenarios or cases of conflict of interest other than just the financial aspect of conflict of interest. Previous studies on COI are mostly conducted among biomedical or medical researchers, thus it is also important to conduct a study on researchers from other fields because it is feared that researchers might take the issue for granted and this may contribute to a higher incidence of research misconduct.

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