Pulse

The Future of Bioethics in Singapore

In December 2000, the Singapore Cabinet formed the Bioethics Advisory Committee (BAC) at the initiative of the then-Deputy Prime Minister Dr Tony Tan. The BAC is an independent national advisory body responsible for examining the ethical, legal and social issues arising from biomedical research in Singapore. Since its founding, the BAC has consulted different sectors of society, including leaders of faith communities, on a wide range of biomedical research and initiatives.

The National Council of Churches of Singapore (NCCS) has participated in every consultation conducted by the BAC. It has produced substantial written responses and taken part in closed-door discussions. The issues that the Council has engaged with the BAC include:

- Research on human stem cell
- Human tissue research
- Genetic testing and research
- Donation of human eggs for research
- Human-animal combinations for biomedical research
- Use of personal information for biomedical research
- Neuroscience
- Mitochondrial Replacement Therapy

Besides these topics, the Council has also addressed other issues in biomedical ethics through the years which were not within the remit of the BAC. These include:

- The Organ Transplant Act
- Euthanasia
- Human Organ Sale
- Social Egg Freezing
- Advanced Maternity Age in IVF

To mark its 20th anniversary, the BAC will be holding a conference next year on the theme, 'Bioethics Future – Empowering Our Next Generation'. Religious leaders have been invited to participate in a panel discussion at this conference.

Perhaps this is also an appropriate occasion for the Christian community in Singapore to reflect on some of the challenges in the area of biomedical ethics that could lie beyond the horizon. This article provides a brief sketch of some of the issues that the Council will have to address in the months and years ahead.

I have arranged these topics in two main sections. The first section deals with specific issues that developing bio- medical and technological research and application will present and that require rigorous public debate. The second section addresses older issues and themes which must be revisited because of recent developments in research and therapeutic applications.

BIOMEDICAL RESEARCH AND APPLICATIONS

In this section we discuss, albeit very briefly, biomedical researches, technologies, techniques and therapeutic applications that are already on the horizon, but have the potential to develop further and in novel and surprising ways – for which rigorous ethical assessment is needed.

Pandemic Bioethics

The current coronavirus pandemic has raised a number of important issues in bio-medical ethics, ranging from patient care to international collaboration. While many of these ethical issues are not new, they must receive fresh attention with every new global health crisis and amidst the ever-changing contexts of public healthcare services and delivery.

On 3 September 2020, *The Straits Times* reported a speech by PM Lee Hsien Loong in which he underscored the fact that Covid-19 will not be the last public health crisis that the island-nation (and indeed the world) will encounter. He spoke about a Disease X – an unknown pathogen that is highly infectious, deadly and mutates easily – for which we must be prepared. To meet the challenges of future pandemics, Singapore must not only have a world-class team of scientists, infectious disease experts, healthcare professionals and the state-of-the-art medical equipment. It must have a clear moral vision which is at once pragmatic and principled.

While Singapore has done well in its response to the Covid-19 pandemic, much work still needs to be done in working out an ethical framework within which she should respond to future health crises. Although it is certainly true that Singapore 'can apply [the] lessons it has learnt in managing this disease to prepare for future pandemics', as PM Lee puts it, that preparation must also involve developing a clear consensus on the ethics of handling a pandemic.

The issues that need to be discussed in-depth are many. They include:

- Equitable health care in a pandemic, which has to do with how limited healthcare resources should be allocated during a pandemic. This would include the ethics of the pandemic triage and the development and accessibility of a vaccine.
- The necessary public health actions that must be undertaken during a pandemic, such as surveillance, contact-tracing, quarantine, social distancing, control of borders, etc.

- The obligations of healthcare workers to the public during a pandemic, and, conversely, the obligations of the public to healthcare workers.
- The obligations that obtain among countries and the obligations that obtain among intergovernmental organisations. In addition, the question of the politicising of a pandemic must also be raised as an ethical (moral) issue.
- The following principles of healthcare provision must also be given careful attention:
    - Utility. Acting in a way that will produce the greatest good.
    - Efficiency. Maximising the results or good outcomes from a set of (limited) resources.
    - Fairness (Justice). The prevention of discrimination and / or the privileging of certain groups of people, which is not based on their medical condition or need.
- There is a second set of principles that must also be taken seriously:
    - Transparency. The processes and grounds for certain decisions such as the implementation of public testing or lockdown measures must be made available to the public.
    - Reversibility. Policies introduced must be subjected to review and revision in light of more experience or new information.
    - Effectiveness. The principles must be translatable to practice – otherwise they would have no relevance.

Gene-Editing and Germline Modification

The first CRISPR-edited babies created by the Chinese scientists He Jiankui and his team in November 2018 not only generated much controversy but also raised the question of the ethics of embryo-editing and germline modification. In response to this, 18 scientists and bioethicists called for a global moratorium on the creation of gene-edited babies and germline modification. 'We call for a global moratorium on all clinical uses of human germline editing – that is, changing heritable DNA (in sperm, eggs or embryos) to make genetically modified children,' they wrote in the 13 March 2019 issue of *Nature*. However, other scientists have argued that germline modification should be allowed under strict protocols because it has the potential of eliminating genetic diseases for which there is currently no cure.

There are many complex ethical and social issues surrounding embryo-editing and germline modification. These include the dignity and moral status of the human embryo and safety concerns such as off-target genetic effects. But one of the main issues associated with germline modification, which bioethics has not given enough attention to, is our responsibility to future generations. Because germline modification will irreversibly change the genome, which is then transmitted down the line, and because we know very little about how these changes might affect future generations, some bioethicists insist that a bright line must be drawn when it comes to this technology.

Big Data

Another major issue in biomedical ethics has to do with the use of Big Data. The era in which we live has witnessed the unprecedented explosion of data – its collection, sharing and analytics. Known as Big Data, this phenomenon has impacted almost every sector of society – economics, politics, security, science, education, policy-making, and of course, public health and healthcare. For instance, Big Data is indispensable for cutting-edge approaches to the practice of medicine such as precision medicine.

Big Data has caused both stakeholders and society to reconceptualise familiar social and ethical concerns surrounding information technology. According to the Council for Big Data, Ethics and Society, 'Big data's broad ethical consequences strain the familiar conceptual and infrastructural resources of science and technology ethics.' In the area of biomedical research and biomedicine, Big Data poses a number of new challenges that must be taken seriously.

The first area has to do with privacy. In the age of Big Data, the issue of privacy and personal safety has become an even more pressing issue. The recent data breaches in Singapore is a stark reminder that privacy and security are issues that the government cannot take for granted. In July 2018, 1.5 million SingHealth patients' non-medical personal data were stolen, and the records of the medicine dispensed for 160,000 were also taken. In January 2019, it was reported that the personal details and the HIV-positive status of 14,200 people were stolen and posted online.

Another area relates to consent. Traditional approaches to informed consent, where consent is sought from individuals who participate in a single study, no longer applies here. This is because Big Data is designed to reveal unintended and unexpected connections between data points. Finally, Big Data can also lead to the de-humanisation and discrimination of individuals and groups as perceptions are formed on the basis of their digital identities and medical records.

Synthetic Biology

Synthetic biology (Synbio) is another developing area of research that holds great promise in so many different branches of medicine. Synthetic biology is an interdisciplinary in which scientists and engineers create biological systems that do not occur in nature as well as re-engineer existing biological systems to perform novel tasks. Among the many benefits of synthetic biology is that it enables scientists to better understand complex biological processes such as the way in which DNA, cells, organisms and biological systems function. There are many potential applications of synthetic biology such as the creation of new biodegradable plastics, new energy sources and new tools to clean up the environment. In medicine, synthetic biology may help scientists find new ways of manufacturing medicines, including the creation of vaccines.

Needless to say, such a controversial approach to genetic engineering, which involves the creation of DNA microbes and artificial cell parts, have brought many new and complex ethical issues to the fore. One concern has to do with the creation of novel organisms that are not found in nature that are self-replicating. At the

philosophical level, these living machines generate debates on the nature of life itself and whether human beings should create novel forms of life. There is a concern that such organisms, once created, may pose a risk to the natural environment and to humans because it is impossible to predict their development and proliferation. Because these organisms are not part of nature, they may not abide by evolutionary principles that govern natural organisms. This is the question of biosafety, which should not be taken lightly. Finally, there is a concern that these novel organisms can be weaponised.

Nanotechnology

The field of nanotechnology also presents many exciting potentials for biomedicine, just as it also poses ethical and social questions that should not be ignored. Nanotechnology is also called molecular manufacturing. It is a branch of engineering that deals with the design and manufacturing of extremely small electronic devices built at a molecular level of matter (a nanometre is one-billionth of a metre). Nanotechnology can be used in a variety of ways. In the arena of manufacturing, for example, nanotechnology can be used for precision manufacturing, efficient material reuse and miniaturization. In environmental science, nanotechnology can be used for cleaning up toxins, recycling and the reduction of the consumption of resources.

In medicine, nanotechnology's usefulness also presents itself in remarkable ways. Imagine the ability to create robots so small that they are able to navigate swiftly through fluids such as blood to specific destinations to deliver medicine to treat a cancerous tumour. Such nanorobots are able to ensure not only the delivery of medical payloads that are precise but also significantly reduce the side effects of drugs. Besides drug delivery in precision medicine or targeted treatment, nanotechnology can also aid in pharmaceutical creations and surgery with the use of the nanomachine which requires no incision.

Needless to say, the ethical concerns surrounding nanotechnology are complex and serious. There is a danger of self-replicating nanomachines spiralling out of control and multiplying exponentially like viruses. There is also the danger of nanomachines that are created for attacking physical structures or biological organisms ('disassemblers') being accidentally let loose in the environment and going on a rampage to disassemble every structure, biological organism or molecule they encounter. This is called the *gray goo* scenario. Nanotechnology, like synthetic biology, is a dual-use technology. This means that it can be used to benefit as well as harm human beings. Through nanotechnology the same nanorobots that are used to deliver medicine or perform surgery can be weaponised to bring harm to human beings.

Human Enhancement

With the rapid advances in biotechnology, information technology, nanotechnology and pharmaceuticals many believe that humanity is on the cusp of the enhancement revolution. Of course, there is a sense in which we are already familiar with existing technologies and instruments that can enhance human abilities, such as the use of

spectacles or contact lenses to enhance vision. There are also drugs that are already in the market such as modafinil that enhances cognitive performance by improving alertness and memory. But the technologies that are on the horizon that can be used for human enhancement are far more radical and controversial. For example, CRISPR can be used to edit human embryos for non-therapeutic purposes such as determining their cosmetic traits such as hair or eye colour and endowing them with greater intellectual or athletic abilities. CRISPR can be used to engineer synthetic blood that would clot much faster (preventing people from bleeding to death) or to keep a person's arteries free from plague (preventing a heart attack). Nanotechnology can be used to create tiny computers than can interface with the brain to enhance human learning abilities such as acquiring a new language.

With the development of these technologies and their applications, the line that separates therapy and enhancement will be further blurred. Theologians and bioethicists have warned that the culture of human enhancement that results from the technological imperative ('we must do it because we can') will have serious negative consequences to the individual and society as a whole. One of the ways in which enhancement will negatively impact individuals is that it would rob them of a sense of achievement and therefore of meaning. In society, the culture of enhancement will exacerbate inequality by creating two classes of human beings – those who are enhanced and those who are not. The culture of enhancement may also bring about backdoor eugenics in society.

Neuroscience

In 2013 the BAC conducted a consultation on the ethical, legal and social issues in neuroscience research. The NCCS participated in the consultation by producing a written response to the BAC's consultation paper and taking part in the closed-door discussion that followed. To date, the BAC has not produced its final report on this important developing field of research. Without doubt, apart from genetics, neuroscience is the most important and promising fields of scientific research that would not only result in a better understanding of the human brain but would also yield many therapeutic strategies for diseases such as Alzheimer's. But neuroscience has also influenced the way in which we understand ourselves, especially the relationship between the mind (brain) and the body. In other words, this research on the workings of the human brain has profound philosophical implications – it has shaped our understanding of human action and challenged received conceptions of freedom and moral responsibility, and continues to do so.

The branch of biomedical ethics called Neuroethics examines the many moral issues surrounding brain research and their diagnostic and therapeutic applications. This includes brain-imaging, brain enhancement, neurostimulation, neurosurgery, brain-computer interfaces and other forms of cybernetics involving the brain, stem cell therapy to repair the brains of patients with Alzheimer's and Parkinson's diseases, etc. Each of these aspects of neuroscience research and application must be subjected to rigorous ethical evaluation. In addition, the controversial use of sham surgery in neuroscience research (as a placebo) also poses serious ethical problems. The response paper of the Council discusses in some detail the numerous ethical

issues associated with these aspects of neuroscience research. But, as neuroscience is in many ways still in its infancy, more issues will emerge as research in this field advances.

OTHER PERTINENT ISSUES

Apart from the biomedical research and their applications, there are also a number of issues that demand attention in the changing landscape of medical practice. We discuss a selection of these concerns under two heads.

Worrying Trends

A number of disturbing developments have taken place in different areas of medical practice. Some of them are perhaps remote in the context of Singapore while others are quite imminent and pressing.

Assisted Reproductive Technology

There are many issues in ART that bioethics need to address. Here we highlight two that have particular relevance to Singapore: social egg freezing and advanced maternal age in IVF. The first issue has been receiving media attention for some time. MSF has consulted NCCS's view on the matter and the Council has published its position on its website. The Council raised the second issue – advanced maternal age in IVF – with MSF in response to an article in *The Straits Times* which reports the proposal by the PAP Women's Wing to remove the upper age limit of women seeking IVF. MSF met with representatives of the Council and the Council subsequently issued an official statement of its position.

While these two issues are, strictly speaking, not under the purview of the BAC, they are biomedical issues that need to be addressed in the form of a public consultation. As its statement makes clear, the Council does not have any objections to medical egg-freezing as long as proper protocols are observed and the safety of the patient is ensured. But social egg-freezing, which is a lifestyle choice, brings with it numerous ethical and social problems which the government and society must take seriously. In the same way, the ethical and social concerns that would result from the removal of the upper age limit of women seek IVF has prevented the Council from supporting the proposal.

Late-stage Abortion

Abortion has been legalised in Singapore since 1969. Currently, a woman can elect to abort the foetus in her womb up to the second trimester of pregnancy (12 to 24 weeks). In January 2019, *USA Today* reported that New York's Reproductive Health Act was passed, which legalises abortion 'all the way up until birth, for any reason.' The Council views this development with grave concern and hopes that other countries – including Singapore – will strenuously oppose the practice of late-stage

or after-birth abortion, which writers such as Ben Shapiro have labelled as a form of 'infanticide'.

Euthanasia and Organ Procurement

In 2008, the then Health Minister, Khaw Boon Wan, surfaced euthanasia as an ethical issue that Singapore should confront. This statement resulted in a flurry of articles in the local newspapers about the possibility of the legalisation of euthanasia in Singapore. 'Euthanasia is looking like a candidate whose time is nearer than most people would imagine', predicts the editorial of *The Straits Times*. The Council issues a strong statement opposing the legalisation of euthanasia and assisted suicide on 6 November 2008. Thankfully, good ethical judgement prevailed and the issue receded from public discussion and attention.

A growing number of countries in the world are making euthanasia and physician-assisted suicide legal. Countries where these practices are legal are expanding the scope of people eligible to apply to have their lives terminated. Recently, Canada has opened the doors to allowing Canadians who are disabled and who suffer from mental illness to seek medically-assisted death. On 24 February 2020, Prime Minister Justin Trudeau's Liberal government brought forward the assisted death Bill that creates a two-track system to ascertain a person's eligibility: one track for those who are terminally ill, and one track for people who are not. This Bill has provoked a public outcry from Christian leaders and conservatives in Canada.

Another disturbing trend is emerging in the West in which patients suffering from terminal illnesses and who wish to end their lives are encouraged to allow physicians to procure their organs once their lives are terminated. This approach is gaining acceptance, especially in countries where euthanasia and assisted suicide are legal. Some have described this phenomenon as 'death by organ donation'. E. Wesley Ely describes this procedure as 'ending people's lives with their informed consent by taking them to the operating room and, under general anaesthesia, opening their chest and abdomen surgically while they are still alive to remove their vital organs for transplantation into other people.' Supporters of this procedure argue that this is the best way to ensure that the organs procured are of optimal condition for transplantation.

Although Singapore currently has a law against assisting a person to commit suicide, it is not entire inconceivable that the question of the possibility of legalising euthanasia and medically-assisted dying will rear its ugly head again in the future.

Re-visiting Familiar Issues and Concepts

As biomedicine and the accompanying technologies develop, familiar issues in biomedical ethics will take on a new texture and complexity. There is therefore a need to constantly return to these issues to see how new strategies of research or novel therapies necessitate a different approach to them. There are many such issues that can be discussed. However, we have elected to highlight only four for consideration. We will discuss them very briefly.

Informed Consent

For many decades, informed consent is a fundamental element not only in all clinical interactions between a doctor and a patient but also in biomedical research. Informed consent is both a trite law and also professional ethics. It has become an important, albeit imperfect, instrument to prevent abuses in medical research and practice that would violate the dignity and liberty of the human person. Informed consent became an important ethical requirement in the wake of the atrocities of eugenics and human experimentation that took place in Nazi Germany.

However, with the emergence of big science and big data, traditional conceptions of what informed consent entails and the mechanisms that support them are becoming more irrelevant and inapplicable. With regard to medical research, traditional approaches have to do with obtaining the consent of the individual participant of a single study. In the area of big science and big data that support new approaches to medicine, such as precision medicine, these traditional approaches no longer apply. This is because research involving Big Data is designed in such a way to allow for new correlations and unexpected causal pathways. And with data-sharing among research outfits and even governments, it is impossible to limit the extent to which data is used. New approaches to informed consent are therefore needed. 'Broad' or 'blanket' consent mechanisms have been suggested to pre-authorise future secondary analyses. But they are not without problems.

Ownership, Privacy and Security

Related to informed consent is the issue of ownership. The European Economic and Social Committee explains that the issue of ownership 'revolves around how to consider a user's data that was produced after processing the original dataset: are they still a user's data, or do they belong to the company that carried out the analyses? Or to the company that collected the data?'

There are also concerns the privacy and security of individuals from who the data is obtained. The issues of privacy and confidentiality are invariably discussed in the literature on Big Data ethics. Unlike the past when data collection was limited by human perception and cognition, in the era of Big Data the collection of data by information technologies is now automated and autonomous. The scope of the data has also expanded exponentially over the past two decades.

There are many instances of data breaches in recent times. In October 2017, *The New York Times* reported that data breaches in Yahoo in 2013 compromised 3 billion accounts. Other breaches include Marriot International (500 million customers), Linkedln (164 million), Sony's PlayStation Network (77 million), Uber (57 million) and Ashley Madison (3 million). Ethical questions concerning accountability, the protection of individuals and groups, and transparent disclosure and just compensation to victims of data theft must be rigorously debated.

Equity

The developments of bio- medicine and technology have exacerbated the problem of equity. Take, for example, the case of precision medicine. While the objectives of precision medicine are laudable, one must also be aware of the inequalities within societies (and among different countries) that the advance of this cutting-edge approach to health care will introduce and exacerbate. These inequalities can be found at different levels of precision health.

In the realm of research, while certain countries are able to conduct extensive research in precision medicine and perhaps develop sophisticated targeted therapies for some diseases, others struggle with the provision of basic health care to their population. It is also doubtful if these countries can benefit from the products of such research.

Even in countries where advanced research in precision medicine is being conducted, it is not necessarily the case that the members of disadvantaged populations can benefit from its therapeutic outcomes. This is because the price of targeted therapies is on average well above the median salary, and unless they are heavily subsidised, a certain sector of the population will never have access to them even though the therapies in question are relevant to the health needs of that sector. The tragic fact is that sometimes the group that has contributed the most to a particular research stands to benefit the least from the therapeutic outcomes of the research.

Trust

Finally, trust. Much attention has been given to the issue of trust in modern transactions, and in data-sharing trust is a very important factor. Many writers have argued that instruments such as informed consent have failed to secure trust. As bioethicists like Onora O'Neill have argued, trust is based on the trustworthiness of its object. In the case of data sharing, the agency gains the trust of the public only if it is transparent and accountable, that is, if information about its management and its decisions are easily accessed and its procedures and protocols are clear. Trust is also connected with the willingness of the institution or agency to provide compensation or protection to parties that are harmed, either through negligence or accident.

CONCLUDING REMARKS

Since its inception the BAC has consulted the leaders of faith communities on all the main research initiatives the government intends to pursue. It has taken the different religious views seriously even though, quite understandably, it has to make its decisions on the basis of public reasoning. Consulting the religious leaders is important because Singapore is a multi-religious society where the different faith communities have played a significant role in nation building. It is also heartening that that religious views are taken seriously by the BAC because bioethics is too important to be confined only to scientists, policy makers, and certain stakeholders. Bio- medicine and technology impact all of society, and the shaping of public policies

concerning research and application should involve as many sectors of society as possible.

The Christian faith has much to contribute to the conversation on the ethical and social implications of bio- medicine and technology. Its understanding of what it means to be human, of the sanctity of human life and the value of every individual, of the nature and purposes of science, medicine and technology, of human rights and liberties, of human dignity and integrity, of the nature of the created order and the value of non-human creatures, and its vision of society and the common good have something profound to say about every cultural endeavour, including medicine, science and technology. And most significantly, the moral compass that it is able to provide will put a check on the technological imperative – the tyranny of the possible – that may well prevent humankind from taking a self-destructive path.

In short, the Christian faith can sound the needful reminder that we should not do something simply because we can. In the wise words of the great Methodist ethicist Paul Ramsey of the last century, 'The good things that men do can be made complete only by the things they refuse to do.'

Roland Chia