

# Health and Human Rights

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In this lecture on health and human rights, there are a few objectives I would like to cover. First, I shall highlight violations of human rights in health research and clinical settings. Second, I shall describe the origins of human rights for health – its beginning and progress. Third, I shall define the term ‘human rights’ and the components of human rights in health. My final objective is to discuss areas of controversy in health and human rights, such as Caesarean section or abortion on maternal request – where do we stand on this? As Singapore Medical Association (SMA) President, Dr Wong Tien Hua, pointed out in his welcome address, the problem lies in differentiating between a right and a privilege. For example, everyone in this room says, ‘No smoking is allowed’, but one person – a smoker – says, ‘This is my right’. If we allow him to smoke, we are giving him a privilege. However, if five people decide to smoke, we have the right to drive them out because as a larger community, our rights override the rights of the individual or that of the five people. That is why, as Dr Wong mentioned earlier, when it comes to infectious diseases, we may sometimes have to infringe on the rights of an individual or a small group because the community’s rights override those of the individual or that of a small group.

My interest in health and human rights started a long time ago. When I was the president of the British Medical Association (BMA), we started organising workshops on health and human rights for medical students, which are still ongoing today. It may be worthwhile for SMA to consider organising such workshops for its doctors, as I have found them to be very useful. I believe that professional organisations have a role to play in championing health and human rights. For instance, the World Medical Association (WMA) meetings, where national medical associations gather annually, is a good platform for the profession to collectively make a stand for human rights and health, such as objecting to doctors being forced to perform torture in some countries.

## ORIGINS OF HUMAN RIGHTS AND HEALTH

In 1776, Thomas Jefferson, the third President of the United States (US), penned these words: “*We hold these truths to be self-evident, that all men are created equal, that they are endowed by their Creator with certain unalienable Rights, that among these are Life, Liberty and the pursuit of Happiness.*”<sup>(1)</sup> Centuries later, these words are still echoed by American Presidents. In truth, since Jefferson first penned those words, it took another nearly 200 years for President Lyndon Johnson to pass the Civil Rights Act in 1964,<sup>(2)</sup> enabling the blacks to have equal rights with the whites. Before this historic event, many others had lost their lives fighting for human rights, the most prominent being President Abraham Lincoln, who started the civil rights movement and won the war to abolish slavery.

With the formation of the United Nations (UN), the issue of health and human rights was brought into sharp focus, with the UN Universal Declaration of Human Rights affirming the right of every person to enjoy a high, attainable standard of physical and mental health.<sup>(3)</sup>

## Human rights and research

Doctors have always been thought of as healers and caretakers of the sick and infirm. In ancient civilisations, the medicine man was often trusted and respected, and even considered sacred in some cultures. The Holocaust during the Second World War revealed a blatant disregard for health and human rights. The perpetrators were doctors whose practice of medicine was egregious, outrageous and shocking. They not only violated the trust placed in them by patients, but also committed appalling acts against humanity. The most painful truth is that many of these doctors managed to eventually escape to countries like Ecuador and Brazil, while the patients were left to suffer. The doctors of the Third Reich performed various types of experiments on patients. I shall elaborate on a few of them.

Freezing or hypothermia experiments were conducted to simulate conditions suffered by the German armies on the Eastern Front, as thousands of German soldiers had frozen to death while fighting the Russians. These experiments were conducted under the supervision of Dr Sigmund Rascher, who reported directly to the police chief, Heinrich Himmler. The results of the experiments were reported at a medical conference entitled ‘Medical Problems Arising from Sea and Winter’. The two main aims of the study were to establish: (1) how long it takes to lower body temperature till death; and (2) how to best resuscitate the frozen victim. Two methods of freezing the body to sub-zero temperature were used: immersion in an icy vat of water or standing naked outside in sub-zero temperature. Naturally, most of the victims – young, healthy Jews and Russians – died when their body temperature fell below 25°C.

Next, warming experiments were conducted to determine how to best resuscitate frozen German soldiers. The methods used for warming were equally cruel. Victims were placed under a sun lamp to reheat their bodies. Most of these victims died of burns, as their bodies were overheated. Another method was internal irrigation, where water that had been heated to near-blistering temperature was forcefully irrigated into the victims’ stomach, bladder and intestines. Most died from such cruel treatments. Other failed methods included hot baths and warming via body heat or forced copulation.

Another experiment was conducted on twin children by a famous doctor named Josef Mengele. At Auschwitz, he carried out twin-to-twin transfusions, as well as stitching, castration and sterilisation. Many twins had their limbs and organs removed in macabre surgical procedures without anaesthetic.

The victims were usually murdered when the experiment was over. Known to the children as 'Uncle Mengele', he was said to have brought candies and clothes for the children whom he later experimented on. Mengele finally escaped to Brazil, where he was never caught despite international efforts to track him down. He died in 1979.

Nazi doctors also conducted sterilisation experiments to find cheap and effective ways of performing mass sterilisation. The experiments involved mutilating the genitals of thousands of inmates and injecting caustic substances into the cervix or uterus of women, which caused intense pain, ovarian inflammation and abdominal spasm or haemorrhage. Men were subjected to testicular radiation and subsequently castrated to ascertain the pathological changes in their testes.

After the war, 23 German doctors were prosecuted in what was famously known as the Nuremberg Doctors Trial.<sup>(4)</sup> The trial lasted 140 days and the testimonies of 85 witnesses were heard. Eventually, 16 doctors were found guilty: seven were executed; seven were later acquitted, as they did not actively participate in the experiments; and the fate of the remaining two doctors was unknown. The Doctors Trial gave rise to the Nuremberg Code,<sup>(5)</sup> a set of ten ethical principles for human experimentation, or what we would call 'good clinical research practice' today. I shall briefly run through each of the ten points.

1. Voluntary consent is absolutely essential. Today, we have good clinical research practice codes and agencies that supervise research. Patients are able to exercise free choice without force, deceit or duress. Importantly, they should know exactly what will happen when they participate in an experiment. Patients must also give their consent before participation. It is also the duty and responsibility of the person who takes the consent to explain exactly what goes on during the experiment and what consequences or harmful effects there might be.
2. The experiment should yield results that are fruitful for the good of society and unprocurable by other methods or means.
3. The experiment should be designed and based on the results of animal experimentation.
4. The experiment should be conducted in a manner that avoids unnecessary physical and mental suffering or injury.
5. No experiment should be conducted where there is a reason to believe that death or disability will occur.
6. The degree of risk should never exceed that determined by the humanitarian importance of the problem to be solved by the experiment.
7. There should be proper preparations made and an adequate facility available to protect the subject from injury or harm, should something go wrong.
8. The experiment should be conducted only by scientifically qualified people.
9. During the course of the experiment, the human subject should be at liberty to withdraw. This is part and parcel of taking consent today. In the United Kingdom (UK), besides informed consent, the subject's general practitioner has to be informed of his or her participation.

10. The scientist in charge is responsible to stop the experiment or withdraw the subject and terminate the experiment at any stage, if there is cause to believe that continuation of the experiment could result in harm to the subject.

### Human rights and clinical practice

Although there were improvements to the treatment of human subjects because of the Nuremberg Code, unethical medical experiments continued even into the 1960s and '70s. Between 1963 and 1971, the testicles of 67 Oregon and Washington state prison inmates were exposed to X-rays to determine the effects of radiation on sperm production; the inmates were never informed that exposure to radiation might cause cancer. From 1946 to 1956, 19 mentally retarded boys from a state residential school in Waltham, Massachusetts, were given radioactive iron and calcium to gather information about the metabolism of these substances; again, the subjects' parents were not informed about the radioactive agents. In 1956, subjects in an experiment conducted in Rochester were injected with plutonium<sup>(6)</sup> – some without consent and others without being fully informed. The results of this study did not become public knowledge until 1993. Other ethically questionable studies included microcephaly experiments where the skulls of intellectually disabled persons were opened to allow the brain to expand, and the Willowbrook hepatitis experiment where 700 mentally retarded children were deliberately infected with the most virulent strains of hepatitis to determine the course of hepatitis and the effectiveness of gamma globulin immunisation.

The experiment that highlighted the full extent of the problem was the Tuskegee Syphilis Study.<sup>(7)</sup> This infamous study, which was conducted with the approval of the US Department of Public Health, spanned nearly 40 years (1932–1970) and aimed to study the natural history of syphilis among 600 black males. The subjects were poor black cotton sharecroppers from Alabama, who were identified to have syphilis. The subjects were never told that they had contracted syphilis, but led to believe that they were receiving treatment for various illnesses. Although penicillin had already been identified as an effective cure for syphilis, the antibiotic was withheld from the subjects. As a result, at least 40 subjects died, and many of the victims' sexual partners also contracted the disease and their babies were born with congenital syphilis.

This unethical experiment only came to light in 1972 and led to the creation of another set of ethical principles. While the Nuremberg Code focused primarily on patient consent in research, the Tuskegee principles included the care of human subjects in experiments (i.e. what should and should not be done clinically). Essentially, the Tuskegee experiments violated the following human rights: the rights to life; health; privacy; confidentiality; autonomous decision-making; to receive and impart information relevant to the subject's health; non-discrimination; freedom from human degradation; and to enjoy the benefits of scientific progress (i.e. the discovery of penicillin as a cure for syphilis).

While the Nuremberg Trial gave rise to a code of ethical principles regarding the research aspects of experiments, the

Tuskegee experiment led to a set of principles regarding clinical services, which was later embedded in the Universal Declaration of Human Rights: *"No one should be subjected to torture or to cruel, inhuman or degrading treatment or punishment"*. Furthermore, the statement is *"non-derogable"*, which means that *"it applies to all people, at all times, in all places"* and *"cannot be negotiated away, nor sidestepped through pressure of circumstance"*.

In 1964, the 18th WMA General Assembly formally adopted the Helsinki Principles<sup>(8)</sup> – a set of ethical principles for medical research involving human subjects – in Finland. Since then, the Declaration of Helsinki has been amended several times. At the last amendment in 2004, it comprised 32 principles, encompassing both the Nuremberg and Tuskegee principles mentioned earlier.

### Human rights and torture

The first aspect of human rights focuses on research, while the second relates to clinical practice. There is yet a third aspect – torture. In September 2014, Amnesty International published a list of 141 countries that still torture their prisoners and suspects of crimes. Guantanamo Bay is one such example. By that time, most of the prisoners held at Guantanamo Bay, Cuba, had already been released. However, some of the remaining detainees who went on hunger strikes were being subjected to force-feeding programmes. Some believed that force-feeding was carried out to aid interrogation, as the force-fed inmates would become so uncomfortable that they would give up the truth on interrogation. This was challenged by the newspapers and the US government under George W Bush did not appear to have taken action. In 2016, President Barack Obama was questioned on his lack of action regarding force-feeding of hunger-striking inmates; he finally took steps toward ending such practices.<sup>(9)</sup>

With regard to torture, the WMA Declaration of Tokyo states: *"The physician shall not countenance, condone or participate in the practice of torture or other forms of cruel, inhuman or degrading procedures, whatever the offence of which the victim of such procedures is suspected, accused or guilty, and whatever the victim's beliefs or motives, and in all situations, including armed conflict and civil strife."* Essentially, medical involvement in torture can be distilled into a few points. The first is that doctors should not be witnesses of torture. Second, they should not have any therapeutic involvement with the victims. Third, if there is forensic involvement, they must honestly declare what has happened with no attempts to cover up. Fourth, they should avoid all complicity – intentional or otherwise. Fifth, they should not participate in the design of torture methods. Finally, they must not actively participate in torture.

One example of human rights and torture is the introduction of forced medical involvement in judicial amputations by Saddam Hussein. In 1994, hundreds of Iraqi doctors – led by the director of Al-Basra Hospital and a leading doctor from Saddam Hospital – carried out a protest strike against judicial amputations. The two leaders of the strike were later executed for refusing to carry

out what they deemed to be unacceptable practices, while some doctors were arrested. Another example is the case of a 25-year-old student who was arrested for protesting in Brazil. He recounted that, while he was detained at the barracks of the 23rd Riflemen's Battalion, a medical officer had not only refused to medicate him even though he was in pain, but also advised his torturers on which part of the body could be hit without leaving a trace.

Dr Wendy Orr, a district surgeon at Eastern Cape, South Africa, who witnessed the torture and abuse of detainees in South African apartheid, said: *"I was confronted on an almost daily basis with some sort of violation of rights of my patients, or some challenge of my own perspective on moral and ethical practice. I can articulate that now, but at the time, I just felt uncomfortable – that things were not OK. I also felt unsure of my own discomfort. No one else I worked with seemed to have a problem. We had never talked about these issues at medical school. There seemed to be no place I could go to discuss my concerns."*

### WHAT ARE HUMAN RIGHTS?

The three areas we talked about – research, clinical practice and torture – all involve human rights issues. There are multiple dimensions to human rights – moral, legal, political and rhetorical, and they are connected in complex ways to fundamental human good. Health rights are not that different from human rights, which can be thought of as a normative legal framework that regulates the relationship between the citizen and state. They are often forged in opposition to various forms of tyranny. The basic claim that underlies human rights is that each person has an irreducible moral status and can therefore demand not to be treated in ways that are incompatible with that moral status. These claims can be made against a duty bearer, such as the state or an officer, and they are universal.

The Geneva Conventions, which were ratified by 196 countries, generally state that: no one shall be punished for carrying out medical activities comparable with medical ethics; no person shall be compelled to perform acts contrary to medical ethics; and no person shall be compelled to give any information concerning the wounded or sick to any party where it would be harmful to the person.

### Rights-based approach to medical practice: ten competencies

For physicians to have a rights-based approach to medical practice, they need to have the competencies to apply the principles of human rights to the daily practice of healthcare.<sup>(10)</sup> There are generally ten accepted competencies that the physician should have. I urge physicians to take time every day to reflect on whether they have violated any of these ten competencies in their practice of medicine.

#### Right to life

Everyone has the right to life. Ask yourself, 'Did I do something that prevented the person from death; could I have done better?' We also must consider the impact of the provision and denial of emergency healthcare services, and evaluate how healthcare

systems can ensure or compromise a patient's right to live. For instance, your juniors are treating a patient that is not under your direct care, but are you giving them the necessary support to look after the patient well? Sometimes, we may be indirectly denying someone the right to live.

### ***Right to health***

Everyone has the right to the highest attainable standards of physical and mental health. We must consider the impact of availability, acceptability, accessibility and quality of care in health outcomes, as well as assess the quality of health services for diverse populations in the community. There should also be evaluation of public health measures for screening of diseases to prolong life expectancy. In the US, Obamacare (i.e. the Affordable Care Act) is trying to address some of these issues, as some patients in the country are deprived of healthcare due to a lack of funding.

### ***Right to privacy***

During consultation, examination and treatment of a patient in a private space, physicians should act in a manner that ensures privacy and respect. For instance, the doctor should not be talking on the phone about another patient while attending to a patient. Physicians should also recognise the need for a third party or chaperone to be present in some cases. However, it is important that these individuals are strictly instructed to keep the information shared within the clinic setting private, especially when it involves sensitive issues such as sexually transmitted diseases, cancers, congenital malformations or donor information in artificial insemination. There is also a need to acknowledge and accommodate varying cultural attitudes toward modesty.

### ***Right to confidentiality***

Physicians must maintain patient confidentiality and avoid unnecessary disclosure of information regarding a patient's health status. It is also prudent to communicate to patients regarding how the clinic maintains the confidentiality of their written and digital personal information. One should also carefully consider the potential harm and benefit, as well the laws regarding confidentiality, before releasing a patient's confidential information to a third party.

### ***Right to autonomy and decision-making***

This means that patients have the right to make decisions concerning their own healthcare. Physicians need to acknowledge and respect this while considering the medical, social and cultural factors surrounding the patient's decision-making. The capacity of an individual at any age to give consent should also be evaluated. In the case of young patients, physicians need to ensure that the best interests and evolving capacity of the child are considered when obtaining consent from children and their legal guardians. The Royal College of Surgeons of England requires physicians to discuss with their patients the treatment options available, but allow them to make the final decision based on this information. As patients are increasingly accessing health information on the

Internet, it has become a necessity for doctors to engage their patients in discussion about their health.

### ***Right to information***

Patients have the right to know the risks and benefits of accepting or declining certain therapies, as well as any alternative treatments available. Physicians need to communicate this information to their patients in culturally sensitive and understandable language, as well as offer full disclosure of test results, unless requested otherwise by the patient. It is also useful to provide patients with literature on the subject matter. In many UK hospitals, patients can key in a subject matter on computers located in the hospitals and have the information printed out at the touch of a button.

### ***Right to non-discrimination***

No one should be subjected to discrimination on any grounds while receiving healthcare. Religious practices and societal and cultural roles should not impact a patient's access to healthcare. Physicians should provide optimal healthcare services and establish mutually respectful relationships with men and women of all backgrounds and abilities.

### ***Right to decide the number and spacing of children***

Every woman has the right to decide freely and responsibly the number and spacing of children, as well as to have access to information and the means that enable them to exercise these rights. Unfortunately, this is still a major problem worldwide. In many countries, women do not have a say regarding their sexual and reproductive functions. Ironically, decisions on number and spacing of children are often made by the husband or mother-in-law. Globally, maternal mortality is about 300,000 deaths per year.<sup>(11)</sup> It is believed that maternal mortality can be reduced by 30% with contraception alone and by another 13% through the provision of safe abortion care.<sup>(12)</sup> Thus, it is imperative to provide women with preconception counselling, as well as comprehensive information on and access to different methods of contraception and abortion, in areas where it is legal.

### ***Right to freedom from inhumane and degrading treatment***

As physicians, we need to identify and assist victims of physical, psychological and sexual violence or abuse, and act as advocates against prevalent harmful practices such as female genital mutilation, early marriage and polygamy. In the UK, doctors sometimes encounter women who they suspect have been sexually, physically or verbally abused by their husbands. In the presence of their husbands, these women often keep silent, but it is our responsibility to find out. Sometimes we send the husband on errands in order to have a chat with the patient. I ask the patient three questions. The first is 'Have you been abused in any way, verbally or physically?' If she answers in the affirmative, I would follow up with the next questions, 'Do you want to talk about it?' and 'Do you want any help?' If I suspect that the patient may have a psychiatric problem, I ask another set of three questions: 'Have you had any psychiatric problems?' 'Do you feel hopeless?'



and 'Do you feel depressed?' It is important that we identify the problems and help the patients as best we can.

### ***Right to benefit from scientific progress***

Physicians play an important role in ensuring that their patients enjoy the benefits of scientific progress and its applications. We need to continually access and critically evaluate new information from a variety of sources, so that we can inform patients of new evidence-based practices and medical therapies to effectively help them plan their healthcare. In my travels, I have observed that some senior physicians and obstetricians in many countries do not see the need to attend continuing medical education (CME) meetings. As a result, they are unaware of the latest medical developments or surgical techniques. For example, a survey that studied hospital episode statistics was conducted by the Royal College of Obstetricians and Gynaecologists (RCOG) during my presidency. One of the questions was on treatment for heavy menstrual bleeding in women. In some hospitals, 80% of the doctors would perform hysterectomy on the patient, whereas only 20% of doctors in other hospitals would consider hysterectomy. Why is there a difference? It is because the latter 20% are managing the bleeding with simple Mirena coil, medication or endometrial ablation. The 80% who do hysterectomy are those who do not attend CME events; truth be told, some of these doctors may not have even heard of the effectiveness of Mirena or endometrial ablation, nor are they interested to learn about these new techniques.

## **CONTROVERSY IN HEALTH AND HUMAN RIGHTS**

Whenever a medical problem arises in a case, there are five key questions that should be asked: (1) What are the medical problems and health issues in this case? (2) What are the threats to human rights posed by this scenario? (3) How does the healthcare system support or infringe upon human rights? (4) What are the local practices and regulations that affect the practitioner's ability to deliver human rights-based patient care? (5) How could this healthcare encounter be improved to respect human rights and ensure quality healthcare? These questions will be explored further.

### **Right to life: incomplete miscarriage**

Incomplete miscarriage is a common medical problem in many countries. In some countries where abortion is illegal, many women are sent to jail because they are suspected of procuring an illegal abortion. However, it is difficult to differentiate between spontaneous incomplete miscarriage and procured incomplete miscarriage. When a woman presents to the hospital with bleeding and incomplete miscarriage, the authorities tend to assume that she has done something to induce the miscarriage. In such cases, physicians must be competent to apply the 'right to life' principle to their practice. They should understand the impact of provision and denial of emergency healthcare, and be ready to provide emergency lifesaving treatment independent of their own personal beliefs. As physicians, we play a part in improving the healthcare system so that it ensures the right to life for every patient.

I shall illustrate this point with the case of SJ, a 21-year-old mother of two from an African country. SJ had walked 7 km to a local clinic to be evaluated for vaginal bleeding. She knew that she was pregnant, as her last period was 14 weeks ago and she also had the familiar signs of early pregnancy such as nausea and breast tenderness. On the previous evening, she had inserted some tablets into her vagina to induce an abortion. The friend who had given her the tablets assured her that the tablets would cause bleeding and make it appear that she was having her normal period. The nurse who attended to SJ performed a vaginal examination and found what appeared to be some retained products of conception in the vagina with an open cervical os, as well as three white tablets, which were identified as misoprostol. The nurse recorded SJ's history and physical examination in a handwritten note, and handed her an envelope with the note and a plastic specimen container with the three tablets. She then called for an ambulance to transfer SJ to the district hospital. Approximately two hours later, the ambulance arrived and SJ was transported 100 km to the district hospital. Upon arrival, the doctor reviewed the nurse's notes, examined the tablets and asked: "*Why did you murder your baby?*" He then conducted a cursory examination and added a note, "*Criminal abortion, suspected use of misoprostol*" to her records. Despite her profuse bleeding and rapid pulse, the doctor called for another ambulance to take her to a provincial hospital that was two hours away. SJ continued to bleed throughout the long ambulance ride and was pronounced dead on arrival.

Now, let us examine the case carefully. What are the medical issues? The patient had a miscarriage and was having active bleeding. What is the appropriate management? Should the nurse or doctor have removed the products of conception or left the tablets inside the patient? Is completing the abortion against any religion or law, if it means saving a life? What are the health risks? The health risk of delayed treatment for incomplete miscarriage was continued heavy bleeding, leading to death.

If you look at the case from the health and human rights point of view, it is quite clear that the healthcare providers had violated the patient's right to life from the start to the end. How did the response of each of the healthcare providers threaten the patient's right to life? Since the miscarriage was already in progress and the patient was at risk of dying, the nurse could have given the patient intravenous fluids and retained the tablets when the patient was being transferred to another hospital, because the abortion may have completed if the tablets had not been removed. The nurse could also have inserted a finger and evacuated the uterus – something all nurses are trained to do as part of emergency obstetric functions in these countries. The doctor did not show any empathy to the patient. He could have done a number of things – start an intravenous line, administer antibiotics, evacuate the uterus or perform lifesaving treatment. By doing nothing, both the nurse and doctor had essentially mismanaged the patient and violated her right to life.

The question then is: how should the healthcare provider reconcile his or her own beliefs with the healthcare needs of the

patient? Assuming that the patient had procured an abortion and the healthcare providers have certain religious beliefs, would they be doing something wrong if they had removed the products of conception during an incomplete miscarriage? To complete an already incomplete miscarriage is lifesaving and not against the law or one's religion. Thus, it is important to educate healthcare providers to differentiate between 'initiating' an abortion and 'completing' an abortion.

This is not a problem faced only by African women. Every year, thousands of Irish women travel to England, the Netherlands and other nearby countries to get an abortion, because abortion is illegal in Ireland. These women usually come from more privileged backgrounds and can thus afford to do so. However, the poor who cannot afford to go overseas for legal abortions could end up with clandestine abortions, where there is a higher chance of incomplete miscarriages and infection.

## HEALTH AND HUMAN RIGHTS ADVOCACY

Professional organisations and individuals with high professional status can play a role in championing human rights. I developed an interest in health and human rights after I moved from Singapore to the UK in 1997. At that time, I realised that it is impossible to change things solely by teaching and doing clinical work. To make an impact in healthcare, one has to get involved in 'medical politics'. I had recently arrived in the UK when the report on a confidential enquiry into stillbirths and deaths in infancy was released in 1997.<sup>(13)</sup> As my interest was in fetal surveillance, the report immediately caught my attention. The report revealed that in 1995, there were 873 cases of intrapartum deaths beyond 34 weeks. All the infants, who died either in labour or soon afterwards, were normally formed with no congenital malformations. The report highlighted that 50% of the deaths may not have happened if a different course of action had been taken. The main issues that were identified were: inability to interpret cardiotocograph traces; failure to incorporate clinical picture; delay in taking action; and poor communication. I read the report and felt that something had to be done. So, a colleague and I started to give regular lectures to educate midwives and doctors on some of these issues. They came, listened and read a book or two, but nothing changed.

In 2007, UK Chief Medical Officer Sir Liam Donaldson raised the issue of fetal deaths in the 2006 annual report entitled '500 Missed Opportunities'. The report highlighted the tragic deaths of 500 babies who had been alive and well, but died at between 37 and 42 weeks of pregnancy. What went wrong? Globally, there are about 2.6 million stillbirths each year, and about 1.2 million of these occur during labour and birth.<sup>(14)</sup> There is undoubtedly an urgent need to invest more money in intrapartum care – not only to increase the number of doctors and midwives, but also to acquire more equipment and increase teaching and training, followed by assessment.

A study conducted to determine the relationship between the rate of fetal deaths and the presence/absence of a senior doctor in the delivery suite showed a trend of stillbirths and intrapartum deaths occurring in the early hours of the morning when there were no senior doctors attending to the births.<sup>(15)</sup> This

is evidence for consultant-based delivery services, as serious morbidity and mortality increase without the direct care and supervision of senior doctors. Remote surveillance may lead to higher morbidity.

I shall illustrate this point using the example of a surveillance plane. What would you do if you heard this announcement after boarding the plane: 'I'm going to fly you to London today, but I'm at home. My trainee pilot is going to take you there instead.' You would most certainly get off the plane. This is happening in medical care in the UK. After 5 pm on weekdays, there are no senior doctors around. During the weekends, from 5 pm on Friday till Monday morning, there are no senior doctors around, although the situation is steadily improving. When something goes wrong with a patient, the junior doctor telephones the senior doctor, who instructs him what to do, or he may say something like 'Please carry on'. A junior doctor may be reluctant to admit that he is uncomfortable with doing that procedure and may carry on because he is the only person present to do it. Then something may go wrong.

To overcome some of these issues, during the time I was president of the RCOG, I spoke to personnel from the Ministry of Health and asked for more consultants in obstetrics and gynaecology. I showed some data and explained that without additional consultants, more babies were going to die. Unfortunately, there was a suboptimal response, so I approached a newspaper reporter to write an article on this problem, to be published before the Labour Party conference so that it would get people's attention. The Observer published the article, 'The tragic human cost of NHS baby blunders'.<sup>(16)</sup> In the article, it stated that I did not have a reputation for being outspoken (which is true), but I had felt then that I needed to be a little outspoken, given the dire situation. Eventually, the government increased the budget at the time of implementation of the European working time directive and we received some funding to increase the number of consultants. This is an example of advocacy for babies' rights, but what about the rights of women? Are they being addressed?

Globally, about 300,000 women die from pregnancy and childbirth-related causes.<sup>(11)</sup> It has been reported that about 30% of the women could have been managed by contraception, 15% by safe abortion care and 40% by emergency obstetric care.<sup>(12)</sup> In the UK, reports on confidential enquiries into maternal deaths, 'Saving Mothers' Lives', are published every three years. The 2011 report showed that about 60%–70% of maternal deaths were due to substandard care.<sup>(17)</sup> Although the actual number of deaths was very small and the numbers had dropped dramatically since the 1950s, we still lose mothers to conditions such as cardiac disease, thromboembolism, preeclampsia, postpartum haemorrhage (PPH) and amniotic fluid embolism. The truth is, approximately 60% of maternal deaths happened because we were not doing our job properly; out of these 60%, the consultants were not in attendance some of the time; they were either not told about the problem, or they were told but did not go to the hospital to attend to the case.

Around that same time, two incidents that highlighted the violation of basic human rights in healthcare took place: one in

Northwick Park Hospital, UK, and the other one in University Hospital Galway, Ireland.

### Lessons from Northwick Park Hospital

I shall focus first on Northwick Park Hospital, which delivered 5,000 babies each year. There were ten maternal deaths between 2002 and 2005. Of the 15,000 babies born over the three years, ten women died. Based on the proportion of maternal deaths for the rest of the country (i.e. one in 10,000), there should be fewer maternal deaths (maybe one or two). A review was conducted on the ten cases of maternal deaths. I was appointed by Rt Hon John Reid, the Secretary of State for Health, to chair the support team. We found a number of failings on the part of the hospital, including a lack of response to changes in the patients' condition. A few things stood out in the review. The first was a lack of consultant input, i.e. in six out of ten cases there were no consultants involved. Secondly, there was a delay in informing the consultant of the patient's condition in three cases. Finally, there was a failure to recognise the severity of the patient's problem. To sum it up, some of the ten maternal deaths could have been avoided if the junior doctor had recognised the problem and informed the consultant-in-charge, and if the consultant had been in attendance to manage the patient. The proportion of maternal deaths due to substandard care in Northwick Park Hospital was similar to the confidential enquiries' finding of 60%–70% of maternal deaths.

In 2009, the RCOG established a good practice guideline, 'Responsibility of the Consultant On-call' as a standard to improve women's health.<sup>(18)</sup> The guideline aimed to improve safety, ensure quality of care and provide support for trainees. To summarise, the responsibilities of the consultant on-call included: participation in labour ward duties to ensure safer childbirth; attending to patients with conditions such as major PPH, eclamptic fits and major placenta praevia, or on the trainee's requests; and being present for trial of instrumental delivery and complex or complicated labour/Caesarean sections. This created a big commotion, as some were unwilling to abide by the recommendations. There was even a challenge to me as president at the senior staff conference during the president's question-and-answer session. In response, I told the senior staff that there was sufficient evidence, based on confidential inquiries at Northwick Park Hospital, of the need to bring about this change, and I was not prepared to change or compromise the situation. In times like this, I think it is necessary to be bold and to remain resolute in our stand if we are to provide care according to the principles of human rights.

Establishing a guideline for the responsibility of the consultant on-call<sup>(18)</sup> was the first thing we did. The second thing was training junior doctors to know exactly when to call in the senior doctors. We produced a chart, which is used now in many disciplines, called the Early Warning Obstetric Care chart. The chart uses colour zones to mark deterioration in the patients' conditions; the red zone is a signal to the junior doctor to call in the consultant immediately. However, even with the chart, things were missed. To further help the junior doctors, we recently conducted a study to establish the normal range for obstetric shock after birth, as an aid to estimate blood loss in PPH.<sup>(19)</sup> With the obstetric shock

index or OSI, junior doctors could easily identify a patient who is having PPH and needs blood transfusion.

We also established a clinical governance monitoring tool called a Maternity Dashboard. This tool came about because we noticed that doctors were unaware of what was happening to their patients in their unit; there was no departmental discussion and some doctors did not attend such unit discussions. Basically, the Maternity Dashboard works like the dashboard of a car.<sup>(20)</sup> When we are driving a car, we occasionally check the dashboard to see if the petrol meter is down. When the petrol gauge does not show a red indicator, we continue to drive, although it is still steadily going down as we drive. When the meter shows red, we start to panic because we now need to get to a petrol station urgently. The problem is, we are not bothered unless the meter is red.

The Maternity Dashboard is a monthly chart that provides a powerful, visible way of continually monitoring and assessing how well the unit is functioning. It contains important information such as clinical indicators (e.g. type and number of maternal and neonatal morbidities); workforce schedule (e.g. weekly hours of consultant cover in the labour ward); and other departmental activities (e.g. booking schedule). There is a threshold line or an average for each item. If an item exceeds the threshold, there is an amber flag; if the item exceeds by two standard deviations of the incidence or the incidence exceeds the maximum threshold value, it is reflected as a red flag. All red flags have to be escalated up the ranks, including the hospital's chief executive officer. This problem may reflect the need for more financial resources to correct the problem. Items with amber flags are initially managed by the department, and only get escalated if they remain amber for up to three months.

### Human rights in health: a global problem

Human rights issues are a major problem globally. In relation to women's health challenges in 2015, 289,000 women die in pregnancy and childbirth each year.<sup>(11)</sup> One in three women is sexually or physically abused.<sup>(21)</sup> 225 million women have no access to contraception,<sup>(22)</sup> and 800,000 die from cancers related to reproductive health. There is also increasing maternal mortality due to communicable and non-communicable diseases. The top 20 countries that contribute to maternal and child deaths included Africa, India, China, Afghanistan and Pakistan. China and India, with their large populations, naturally have high maternal and child death rates.<sup>(23)</sup> India produces about 25 million babies every year<sup>(24)</sup> and there are an estimated 12 million abortions. It would be a monumental task to tackle the problem in such a highly populated country. So, what can we do as an international community?

One of the most important steps is to introduce voluntary family spacing with postpartum family planning programmes to communities with unmet needs for contraception. In some communities, it is not uncommon to see women with a nursing baby and several young children, because there is no access to contraception. After giving birth, these women go home and are busy caring for their families, with no time or the means to return to the hospital for postpartum contraception. Currently, a project is underway to introduce contraception

to large numbers of postpartum women in six countries: Sri Lanka, India, Kenya, Tanzania, Nepal and Bangladesh. The FIGO Project aims to institutionalise the practice of offering immediate postpartum intrauterine device (IUD) services in hospitals.<sup>(25)</sup> The programme works this way: before a woman goes into labour, she is counselled regarding postpartum contraception and offered the IUD services; if she gives her consent, a copper IUD will be inserted once her baby and placenta are delivered. This is a project that most governments can afford, as each IUD costs about USD 0.40 and lasts for ten years. The IUD is not only cost-effective and long acting, but is also reversible with high retention and low expulsion rates. Thus, if a woman decides to have a baby three years later, the IUD can be easily removed. It has been shown that a three-year family spacing reduces the incidence of intrauterine growth restriction, preterm births and infant mortality,<sup>(26)</sup> i.e. it is a good thing to space out the family.

I shall turn my attention now to Obamacare, or the Affordable Care Act in the US. In 2010, I was part of a group that was invited to Boston to talk about the management of the UK's National Health Service. About 52 million people in the US were not insured for health in 2009; 13 million were in the reproductive age group. The US Congress aimed to have 32 million out of the 52 million insured by 2019, which leaves 23 million still uninsured after the full implementation of Obamacare. Many American women are uninsured prior to pregnancy, and may possibly have untreated medical conditions. This poses a risk to the mothers and their unborn babies. Based on salary scale, Medicaid was available to citizens and residents if their annual income was USD 24,645 for a family of three; that is the cut-off or poverty line. With the full implementation of Obamacare, 4.5 million women of reproductive age would have become eligible for Medicaid in 2011, which should reduce delays in receiving prenatal care.

The US has a high maternal mortality, compared with Singapore and Japan.<sup>(27)</sup> There are currently many obstacles to care in the US. Here are two examples. A woman with five previous pregnancies, whose immigration status was questionable, presented to the hospital with postpartum bleeding and dizziness. When the patient felt better, she was turned away. At a second hospital, she felt breathless, then bled and collapsed while her insurance was being checked. As it was an emergency, she was immediately attended to and given treatment. She was discharged home three days later with no medication or follow-up. Another woman who had no insurance and lived in a remote reservation for natives died of an undiagnosed heart problem after giving birth to her second child. She did not receive any antenatal or medical care, as the nearest medical facility was two hours away. The problem in the US is that people with no insurance are often denied healthcare unless they present with an emergency. So, if an uninsured person presents with a ruptured appendix, he or she would be given emergency treatment. However, if it is mild appendicitis, the person would likely be turned away without treatment. Maternity care is no different.

Another emerging problem in the US is its rising Caesarean section rates (20.7% in 1996 to 31.8% in 2007).<sup>(28)</sup> It has become

the most common surgical procedure in the US. Vaginal birth after Caesarean (VBAC), on the other hand, has been dropping (35.3% in 1997 to 9.7% in 2006) due to fears of medical litigation.<sup>(29)</sup> In the state of Maryland, any woman who has ever had a Caesarean section was automatically denied vaginal birth for subsequent pregnancies. This resulted in protests by women outside the hospital, who demanded 'evidence-based care' and 'bring back VBAC!' After 18 months of protest, VBAC was finally permitted.<sup>(30)</sup> Another problem is the practice of early elective Caesarean section at 37 or 38 weeks, again due to medicolegal issues. It is estimated that delaying Caesarean section to 39 weeks could lead to savings of about USD 1 billion.<sup>(30)</sup>

Thoraya Obaid, former executive director of the United Nations Population Fund (UNFPA), once said: *"It keeps startling me that at the beginning of the 21st century, at a time when we can... explore the depths of the seas and build an international space station, we have not been able to make childbirth safe for all women around the world... This is one of the greatest social inadequacies of our time."*<sup>(30)</sup>

### **Abortion: a woman's right?**

Abortion is a human drama. No woman would unnecessarily subject herself to physical, mental and emotional torture. So, if a woman opts for an abortion, she should not be treated like a criminal; this clearly violates her right to non-discrimination.

In my birth country, Sri Lanka, abortion is a criminal offence, unless the pregnancy puts the woman's life at risk. In 2006, UNFPA estimates that 600–700 illegal abortions are carried out daily in Sri Lanka.<sup>(31)</sup> If the woman is wealthy, she could get a good obstetrician to perform the deed without public knowledge, but if she does not have the money and has no access to a qualified obstetrician, the abortion is usually clandestine. The majority of abortions in Sri Lanka are unsafe, as they are performed illegally under septic conditions by underqualified people. About 12% of maternal deaths are due to septic abortions.<sup>(32)</sup> One can imagine the human tragedy in such situations. Generally, these abortions are done in women aged 35–39 years who already have children. About 15% of emergency gynaecological admissions are for such types of incomplete abortions.

There was an attempt in 2013 to propose an amendment to the law on abortion to allow for termination of pregnancy in special cases, such as rape or incest and congenital abnormalities that were incompatible with life. However, the Amendment Bill was withdrawn by the then-Minister of Justice and was not voted on in Parliament. Thus, the amendment to the abortion law was not passed.<sup>(33)</sup>

### **Lessons from University Hospital Galway**

I shall now talk about the second incident mentioned earlier, concerning the violation of basic human rights in healthcare. This is a case involving the death of a young mother at University Hospital Galway, Ireland, which sparked a series of protests and demands for an official enquiry into her death. I was appointed by Ireland's Health Minister, Dr James Reilly, to lead a team to review the case in November 2012. The report, which was



completed in June 2013, revealed a series of mistakes.<sup>(34)</sup> This is a summary of the case.

Savita Halappanavar, a dentist, was a 31-year-old primigravida who was 17 weeks pregnant. She presented to the hospital with a backache and lower abdominal pain on the morning of 21 October 2012. The healthcare practitioners examined her and found her to be well enough to be discharged. In the afternoon, the patient noticed that her membranes were bulging out of her vagina, so she pushed them back in and returned to the hospital the same afternoon. The doctor and midwife checked her abdominally and vaginally, but did not use a speculum. They did not notice any bulging membranes. A full blood count (FBC) was ordered and the patient was hospitalised for observation. However, no doctor reviewed her test results, which showed a white blood cell count of 16,000. During the enquiry, when questioned why no one had reviewed the patient's test results, the doctor who ordered the FBC, the ward doctor and midwife all insisted that it was not their responsibility to check the results.

The next day, a consultant examined the patient and found that her blood pressure was normal with a pulse rate of 95–100 bpm. Fetal heartbeat was present. The maternal pulse and blood pressure were supposed to be checked four times a day at four-hour intervals, but they were only checked twice each day. By evening, the patient was having nausea and vomiting, and was unable to eat. She was already septic by then, but no one seemed to have noticed it. Her inability to eat was attributed to her preference for non-Western food. When the patient's membranes ruptured, she was put on erythromycin. In the early hours of the morning, the patient was given extra blankets, as she was feeling cold and had chattering of teeth. She continued to feel unwell and had a pulse rate of 105 bpm. At that time, the house officer who came to check on the patient decided not to disturb her, as she was asleep. A few hours later, her pulse rate increased to 160 bpm and there was a foul-smelling discharge. Fetal heart beat was still present.

The house officer started the patient on IV fluids and antibiotics, and informed the registrar at three or four o'clock in the morning. The registrar did nothing and waited for the consultant to arrive at eight o'clock. When the consultant arrived for the ward rounds, she was not informed of the brownish, foul-smelling discharge. As the fetal heartbeat was still present, the consultant continued to observe her condition. On the same morning, the patient's condition rapidly deteriorated. She went into septic shock followed by multi-organ failure, and died.

The Health Service Executive clinical review report was described by Dr Reilly, the Health Minister, as "*hard-hitting... spares nobody and doesn't pull any punches*". It identified three main factors that led to Ms Halappanavar's death: (1) failure to adhere to clinical guidelines for prompt and effective management of sepsis when it was diagnosed; (2) failure to offer all management options; and (3) inadequate assessment and monitoring.

In my official report, I had also included the statements, "*The Irish abortion law was a key factor... Confusion about the Irish law was a material factor in this death...*" In my interview with the press, I said that I would have terminated the pregnancy if

an infection had been found to be present. When asked if the patient should have had a termination from a purely medical point of view, I replied that termination should be made possible when there is a risk to the health of the mother, as distinct from her life. This is because even if the termination had been done earlier or not at all, the patient's health would have already been jeopardised by that time; she could end up with pelvic inflammation disease or tubal blockage.

The final outcome of the enquiry was that medical recommendations, such as guidelines, induction programme, ISBAR (**I**dentify, **S**ituation, **B**ackground, **A**ssessment and **R**ecommendation), escalation pathway, multidisciplinary team, were implemented. A change in legislature was also requested for termination of pregnancy to be allowed if there is an immediate threat to life or permanent ill health. Eventually, the legislation was passed allowing termination of pregnancy for only immediate threat to life. Although we have scored a point for human rights, my views are that the new abortion law will still not prevent Savita-type of deaths because infections can escalate rapidly and rampantly; one moment, there can be no threat to life, but the patient could take a very bad turn within an hour. So, there is more that needs to be done.

Finally, I would like to end my lecture by introducing you to an organisation called The Global Library of Women's Medicine (GLOWM), for which I am the editor-in-chief. There is a section called Women's Rights, Health and Empowerment. The GLOWM website (<http://www.glowm.com/>) provides plenty of useful information on health and human rights issues.<sup>(10)</sup> Before I end, I would also like to present the SMA with three mementos: a book on the history of BMA; a handbook on the medical profession and human rights published by BMA; and a medallion commemorating the human rights declaration of 1948.

In conclusion, human rights abuse in health happens every day, both in research and clinical practice. As healthcare practitioners, we need to be conscious of the ten health-related human rights in our daily practice. More importantly, we must not be a participant in human rights abuses. If you are ever forced to participate in any inhumane activities, you should seek help from national or international organisations. Finally, if you have spare time, consider volunteering for worthy causes in places where people are deprived of human rights. Remember, it is the right of these individuals to enjoy good health.

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### About the Lecturer

Sir Sabaratnam Arulkumaran's research and clinical interests are in understanding and improving the quality of life for women and newborn babies. He has been in clinical practice for 37 years and in research and teaching for 25 years. He joined St George's, University of London, as a professor and head of Obstetrics and Gynaecology in 2001. Previously, he held posts in a number of high-profile institutions, including the National University of Singapore (NUS) and University of Nottingham. He is a past president of the Royal College of Obstetricians and Gynaecologists (RCOG), British Medical Association and International Federation of Obstetrics and Gynaecology. After obtaining membership of the RCOG and fellowship of the Royal College of Surgeons by examination, he obtained his MD and PhD by research from NUS. In June 2009, he was appointed as Knight Bachelor by Her Majesty the Queen of England for his services rendered to medicine and healthcare in the United Kingdom.

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