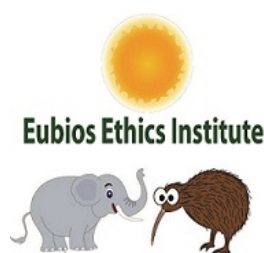


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## Editorial: Approaches to dignity

One of the core principles of bioethics is dignity. The three papers in this issue present different windows on the theme of dignity, and help us reflect on how this very important concept, that has always been very difficult to define, can be better understood through our reflection on the application of the principle in these three examples.

Sylvia Croydon in her analysis of the public discussion and policy on the use of human embryonic stem (ES) cells in Japan, an issue which is often argued to affect the dignity of human embryos. The ES cell debates include those on the use of science because of fears that some research might infringe human dignity. The analysis also shows how national pride that is generated with the awarding of a Nobel prize can be manipulated by the media and scientific community to trump questions over the use of embryonic stem cell lines. Among the global community, Japan lies in a middle ground between countries that permit the use of human embryos for regenerative medical research, and countries which oppose it because of their strict limitations on the use of the human embryo. There are broader aspects of how a debate on the importance of respect for your human dignity could

be significantly shaped by euphoric discussions of the power of scientific endeavor.

R.R> Kishore looks at a vulnerable group of human persons, seniors. How is it possible to enhance the sense of self dignity that some people struggle with at the most senior years of aging. Gerontology is also a field of medicine looking at issues of aging. The paper reflects on a number of issues that we will all most likely face if we live long enough.

Yew Wong Chin et al. explore the intrinsic dignity when indigenous people are connected to their land. The sense of place and space is critical for dignity, not only for indigenous people whose cosmological perspective is clearly linked to particular land, but it's also through having a land that we can call our home many person's identity and dignity is enhanced. If you doubt it, look in the eyes of a homeless person who are wandering and often disjointed from their place and/or sense of self-worth. Economic pressures that lead people into poverty are also critical to a person's sense of worth. In human development, we can see that we are not islands of distinct individuals, but our sense of self dignity is intrinsically linked to our spiritual and mental capacity, being mindful with our own existence, having a linkage and place to call our own. Often this is linked through our heritage to our ancestral lands and ancestral, identities and beliefs. Our dignity is also dependent on how we treat other beings, both human beings, and other beings in a ecocentric perspective.

The tools that are used for the analysis of these papers, include anthropology, psychology, sociology, historical analysis, and science and technology studies to mention just a few aspects of the broad themes that shape biographical discourse and analysis. I hope that we can see more papers from diverse approaches, exploring these themes that are so critical in the world where we still may find it difficult to define human dignity.

- Darryl Macer

## Just Between You, Me and the Gatepost: How Shinya Yamanaka's Discovery was Used to Sidestep Public Opinion in the Efforts to Establish Human Embryonic Stem Cell Research in Japan

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**Abstract:** On 30 June 2017, after nearly twenty years of stagnation, whereby only five human embryonic stem cell (hESC) lines had been created for use in purely scientific projects, a radical departure from the status quo with hESC research in Japan took place. Specifically, a final of a string of authorizations necessary for the derivation of clinical-grade hESC lines was granted to the developmental biologist Hirofumi Suemori of the Institute for Frontier Life and Medical Sciences at Kyoto University—a scientist who had been involved in the creation of all of Japan's previous hESC lines. Part of the radical nature of this development was that, as per the Act on the Safety of Regenerative Medicine promulgated by the Abe Administration in November 2013, Suemori had the freedom to distribute his cell output most widely, i.e. not only to research laboratories in and out of the country, but also to medical facilities and even private companies anywhere. Within the span of just three years from the point at which Suemori's project entered into full force (2018-2021), the amount of cell lines was generated that was almost double that established in the two decades previously. The present article examines the key role that the advent of the induced pluripotent stem cell by the now Nobel Laureate Shinya Yamanaka played in sidestepping the public debate and ending the stagnation of Japanese hESC research.

**Keywords:** Japan; human embryonic stem cell research; induced pluripotent stem cells; organ donation; public debate

## Introduction

The science using human embryonic stem cells (hESCs) failed to pick up in Japan in the 2000s. For about a decade after the first successful isolation of such cells by the American molecular biologist, James A. Thomson of the University of Wisconsin, Madison, US, only three such cell lines had become established in Japan (Suemori *et al.* 2006). Although the same team that was responsible for this Japanese first—a team at Kyoto University's Institute for Frontier Life and Medical Sciences (InFRONT) working under the leadership of stem cell scientist Norio Nakatsuji—derived to more cells over the next few years, this achievement paled against the background of the fact, for example, that in the United States (US), for example, by the time in 2001 when President George W. Bush famously banned federal funding for research on such cells due to his Christian beliefs and moral scruples, as many as 61 hESC lines had already been in existence.

Even just with private funding, the advancements in hESC research that were made theretofore in the US were grater than those in Japan, where, as scientists have widely argued, there was no indigenous religion, as the Christian one in the US, that stands against the progression with such kind of science. For such claims being expressed by scientists here, see the work of British anthropologist Margaret Sleeboom-Faulkner, who conducted extensive interviews in Japan on the topic around this time (Sleeboom-Faulkner 2008 & 2010). So when, on 30 June 2017, after nearly twenty years of hESCR stagnation, a new project began at Kyoto University to create new Japanese such cell lines, this represented nothing less than a radical departure from the *status quo*.

To explain in greater detail what transpired, a final of a series of authorizations had been granted by the Japanese government authorities to enable one of the younger members of Nakatsuji's former team at InFRONT—Hirofumi Suemori—to generate 20 new cell lines over a period of 10 years. The authorization in question had been granted upon Suemori's filing of an application for this project under the Act on the Safety of Regenerative Medicine (ASRM), which had been promulgated by the Abe Administration in November 2013, arguably for the purpose of propelling the development of a Japanese brand of regenerative medicine based on Shinya

*You can fool all the people some of the time,  
and some of the people all the time,  
but you cannot fool all the people all the time.*  
Abraham Lincoln (1809-1865)

Yamanaka's Nobel Prize winning invention of the induced pluripotent stem cell (iPSC). For more on this see the following webpages: [http://chesr.infront.kyoto-u.ac.jp/?page\\_id=64](http://chesr.infront.kyoto-u.ac.jp/?page_id=64), <https://reprocell.co.jp/wp-content/uploads/2019/01/a287d6d5bd83673bd9b175f2982e0fc9-1.pdf>.

Part of the radical nature of the development regarding Suemori is that, unlike the time when Nakatsuji was still active pre-retirement and when the derived cells could only be used for research, the new ones created under ASRM would be of clinical-grade and therefore distributable to not only research institutions, such as universities, but also to medical facilities and even private companies, who could create products generating profits. The cells, moreover, could be sent anywhere internationally, not just domestically in Japan.

Within just three years from the commencement of Suemori's project (i.e., 2018–2021), an amount of cell lines was generated that was almost double that established in the previous two decades. Indeed, by April 2021, Suemori had succeeded in establishing as many as six new cell lines—five female ones and one male, with the team's efficiency in the derivation of new lines having reportedly jumped in 2022 following certain optimization measures from 7.1% to 45.5%—a development boding well for fulfilling the project's goal of 20 hESC lines over the said 10-year period. Information about and images of these hESCs can be seen at website of the Center for Human ES Cell Research newly established at Kyoto University's Institute for Frontier Life and Medical Sciences on 31 March 2020 ([http://chesr.infront.kyoto-u.ac.jp/?page\\_id=70](http://chesr.infront.kyoto-u.ac.jp/?page_id=70)). (For further detail, see: 9 November 2022, "Successful establishment and development of efficient clinical human ES cell lines and banking of cell lines", <https://www.infront.kyoto-u.ac.jp/en/post-3257/>)

Despite this development being a most radical departure from established policy, the events surrounding Suemori and this new activity in hESCR at Kyoto University has remained largely unnoticed and unnoted in the media and scholarly literature. With the limelight falling on the high-profile iPSCs of Yamanaka, Suemori's new endeavors with hESCs have failed to attract any public attention. The scholarship in this area too seems to have stopped in 2009, when Nakatsuji announced in an interview reported about in the top scientific journal *Nature* that he has dropped the idea of

developing any new such cell lines (Cyranoski 2009).

This was also the same year when Sleeboom-Faulkner reported about hESCR in Japan from the position of it being dead, with no prospect of revival any time soon. Indeed, the starting point for her exploration of the situation in Japan was the question of 'Why did it die?', or rather 'Why did it not take off in the first place' (Sleeboom-Faulkner 2008 & 2010). Since then, despite what was just described above, it had remained the received wisdom that hESCR is dead, and dead as a dead horse, full stop. Astonishingly, everyone, even today, seems satisfied with the statement that Japanese hESCR is nonexistent, nowhere to be seen.

The present article puts the spotlight on the new developments at InFRONT at Kyoto University which has taken place at the shadow of effort to develop regenerative medicine based on the iPSC technology. To foreshadow the argument developed below, instead of seeking to improve the understanding of what exactly is involved in hESC research and thereby truly win the public over to the principled position that it is beneficial, the current Japanese elite—that is, the community of stem cell scientists and the government agencies with jurisdiction in this area—is merely trying to make political capital out of the serendipitous event of it having been a Japanese national who discovered the formula worth a Nobel Prize for reprogramming differentiated adult cells into an embryonic state.

To put it differently, by advancing, at a time when the public's attention is focused firmly on the Nobel Prize-winning technology, research using the material that is still considered as the golden standard in stem cell research—hESCs (Kobold *et al.* 2015; Finkelmeyer 2022), this elite could be said to have *de facto* sidestepped the public opinion.

This area of hESC research is a reference to the fact that many people misunderstand embryos insofar that they think of them as miniature babies or fetuses who suffer in the process of being destroyed for the sake of developing a therapy. As the biologist Richard Dawkins has explained in one of his publications aimed at the general public from the time this debate raged in full force in the United Kingdom, however, embryos do not have a central nervous system, and as such they do not have capacity to

feel any pain. More pain is created by boiling a lobster or cutting the throat of a cow, he says. Or to quote him directly: “[t]he embryo that dies as collateral damage during stem-cell research no more suffers than your hair does when it is cut. It feels no more fear than your toenails do at the menacing approach of the clippers” (Dawkins 2007). It is further worth mentioning that many findings exist that an increase in scientific knowledge within the public will lead to higher support by it for scientific research (some examples of such research include: Miller 1998 & 2004; also, for a result of this kind within the specific context of Japan and the manipulation of editing human embryos, see Uchiyama *et al.* 2018).

### **The 2000s hESCR stalemate research in Japan**

Prior to focusing on the contemporary situation, a more detailed account is in order of the circumstances that resulted in hESCR failing to thrive in Japan in the years after the publication of the Thompson *et al.*'s seminal paper on succeeding to isolate hESCs (Thompson *et al.* 1998). With a view to providing just this kind of account, the scholarship of the British anthropologist Sleeboom-Faulkner is reviewed (Sleeboom-Faulkner 2008 & 2010).

Intrigued by the issue of how developments in hESCR in the West are received in Japan, Sleeboom-Faulkner conducted a range of interviews in Japan in the mid-2000s. What she found with regards to the scientists and bioethicists she approached is that they were very quick to discard the question of the moral status of the human embryo in Japan as irrelevant to this country. They argued to her that ordinary Japanese people do not concern themselves with this question since they are programmed to do so by their culture and religion. The traditions here, unlike those in the West (where, as mentioned earlier, Christian beliefs had become the reason to block such science), she was told, do not attribute any ethical meaning to the embryo. Noting that she sensed an overtone of disbelief in some of her respondents towards the declaration in 2001 by the Bush administration of moratorium on public funding for hESCR on the basis of Christian groups objections on moral grounds, Sleeboom-Faulkner explains how they suggested to her that in Japan there is no worry

that such a moratorium would have to be implemented, because, apart from a few minority groups—such as the organization of feminists and disabled people called the *Yūsei Shisō wo Tou Nettowāku* (Network Questioning Eugenics), the Japanese Association for Spinal Cord Injuries, and some radical Buddhist sects (e.g., the Buddhist Omoto and Seicho no Ie)—the local cultural and religious background had conditioned the people to be disinterested and indifferent to the human embryo.

The evidence that Japanese scientists and bioethicists brought to Sleeboom-Faulkner for the argument of the Japanese people being nonchalant to what happens to the human embryo was the country's abortion rate. Had it not been true that the Japanese see the destruction of human embryos as unproblematic, these informants seem to have argued, Japan would have not practiced abortion on the astonishing scale that it does. Abortion, they argued, has never been a problem in Japan. Expanding on this, the developmental biologist Kazuto Kato, leader of a platform for discussion between scientists and the general public called 'Genomics Square' (Kato, 2005: 374–5) told Sleeboom-Faulkner that there are no cultural canons prohibiting abortion in Japan, with Buddhism, for example, placing more emphasis on issues related to death, rather than on birth (Sleeboom-Faulkner 2008: 87). Similarly, another prominent bioethicist—former Prof. of Law at Kyoto University, Ryuichi Ida—appears to have contrasted, to her and in an earlier work of his (Ida 2002), the religious dogma that the embryo is conceived with the blessing of God with the non-religious Japanese perspective that the latter is the 'germ of life' (*seimei no myōga*), within the context of which it is permissible to use embryos left over after *in vitro* fertilization (IVF) treatment, or supernumerary embryos, for positive ends, such as the development of new therapies to cure disease (*Ibid.*)

The picture portrayed by these scientists, however, starkly contrasted with what Sleeboom-Faulkner observed in her other interviews—e.g., of housewives and Buddhist monks. In particular, she found that the claim of the ethical void surrounding the human embryo in Japan did not actually hold and that the moral status of the embryo was after all a matter of concern for the public here. From her perspective, it would be a misrepresentation to

say that the cultural and religious canons found locally leave, unlike in the West, some kind of void for a ‘proper’ bioethical discussion to emerge—i.e., one that is free of moral scruples about harnessing such human tissue for enhancing old-age life and curing the severely disabled. To underline her point, Sleeboom-Faulkner set out how, paradoxically, the same scientists/bioethicists and policymakers who find the Japanese public to be receptive to hESR, resort to exhortations to obtain their desired material for research—embryos, with consent to use public funds for this not flowing either.

On the basis of this, Sleeboom-Faulkner concluded that the denial by the Japanese scientific elite that the public has any concerns about the use of the human embryo in the laboratory for research made it so that there was simply no room for the debate to happen and the resources for research (embryos and funds) to materialize. The public, she suggested, remained unengaged, with the fact that it did have significant moral scruples about this kind of research becoming expressed in the form of the latter virtually coming to a halt.

### **The recent reinvigoration of Japan’s hESCR**

Whilst public debate on hESCR continued to be nonexistent in Japan, at the background of the iPSCs euphoria, the above-mentioned authorization was quietly given in 2017 to Suemori. Although the permission to create clinical-grade hESCs constituted a radical turn in policy, this failed to receive the attention it deserves as such in the media and scholarship. Insofar that this change of course was not based on an open public debate, it comes across as if political opportunism was at play by the elite class of scientists and government officials, or, other words, political tactics were used *vis-à-vis* the populace. Indeed, and somewhat paradoxically, had it not been for this research falling in obscurity behind the iPSC one, it seems unlikely that it would have progressed as it did. It was only owing to the public gaze having become firmly fixed on the iPSC technology, with publicity campaigns and targeted funding programs heightening the public expectations for quick miracles, that an opportunity was

created for the scientific and political establishment to trigger the hESCR that still stands as key to the development of regenerative medicine.

To this day, discussions are still lacking about the moral status of the human embryo in Japan. Simultaneously, Japan’s hESC science has now begun to regain the ground it lost during the 2000s and the 2010s in the global race towards the realization of regenerative medicine. If there is anything at all said in the media in the way of explaining this development, it is the justification, made only in obscure outlets, that the energizing of the hESCR is an emergency, make-do measure that needs to be taken in order to bring the home-grown iPSC project, in which the country enjoys a lead, to fruition<sup>1</sup>. Taking advantage of the stardom and publicity of the Nobel Prize-winning iPSC technology, the Japanese elite can be seen as advancing in the shadows the hESCR agenda, whilst perpetuating the ‘hackneyed’ rhetoric, as Sleeboom-Faulkner called it, of a supposed domestic moral vacuity surrounding the human embryo. To give just one example where the persistent with this rhetoric is evident, in a 2020 publication arguing for the advancement of Japanese human heritable genome editing research, the Hokkaido University bioethicist Tetsuya Ishii wrote that:

*“...religious beliefs are part of the discussion about human reproduction and family-building too. Some religious groups largely accept reproductive medicine, while others condemn some or all types of reproductive medicine. Often, religious beliefs shape the discussion on the acceptable use of reproductive medicine, but not so much in Japan since there is no state religion. Article 20 of the Constitution of Japan stipulates: ‘Freedom of religion is guaranteed to all. No religious organization shall receive any privileges from the State, nor exercise any political authority.’ Moreover, a majority of Japanese are not affiliated with religion. The Pew Research Center Religion and Public Life Project 2010 showed that 57% of Japanese respondents answered that they are unaffiliated with religion,*

<sup>1</sup> Sankei Shimbun, 18 September 2017, *Funin chiryō no haki jusei-ran de “nanbyō chiryō wo”: Futatabi kyakkō wo abiru ES saibō, saisei iryō he iPS saibō to “ryōrin”* [Treating Incurable Diseases with Left-over Embryos from IVF: ES Cells are Receiving Attention Again, Playing the Part of the Second Wheel to iPSCs in Regenerative Medicine Advancement], <https://www.sankei.com/article/20170918-Z52TDCVTOJLBPFA5I5735DFEI/>.

*whereas 36.2% of them answered that they are Buddhists. Nearly all forms of Buddhism currently support reproductive medicine.*

*... While in the West 'ethical concerns' are the soul of many biomedical regulations, in Japan it is a concern with safety and the impact that activities might have on society that is paramount (Ishii 2020, 466-7)."*

What this statement seems to suggest is that the ethical concerns prevalent elsewhere with regards to the morality of destroying human embryos for research are irrelevant here. Insofar that this is the case, Ishii clearly comes very close to what Ida and Kato, or indeed Sleeboom-Faulkner's other scientist-interviewees, said about a decade and a half earlier on the subject. the current establishment and proceeds with cultivation at the background of hESC science.

In short, simultaneously with trying to stop at the early stages the development of a debate on the moral status of the human embryo, Japan's establishment is proceeding with the cultivation and nurturing of hESC science.

### **The question of public debate: Does it really work for unblocking a controversial science?**

Sleeboom-Faulkner contribution to the scholarship on Japanese hESCR at the end of the 2000s did not stop at her pointing out at the inconsistencies in the local scientists' arguments. Indeed, she went further, offering constructively a comparison between the stalemate found here and that which existed for three whole decades with regards to cadaveric organ donation, where an intuitive public opposition also exists. Towards the goal of breaking the deadlock reached on hESCR, she pointed out the crucial role which she thought public debate played in ending the moratorium with respect to organ transplantation surgeries. As she noted, the moratorium that followed the infamous 1968 'Wada case'—whereby the doctor who performed Japan's first heart transplant was accused of manslaughter over the brain-death diagnosis of the donor involved—was only overcome when a ministerial committee directed the question to the Japanese people of what the definition of 'death' should be. Following this, a flurry of popular books appeared on the subject, with the upshot being

the enactment of the 1997 Organ Transplantation Act, which, as has been documented prior to Sleeboom-Faulkner's writing (Morioka 2001, see also Lock 2001), left room for interpretation to those directly concerned. What Sleeboom-Faulkner stressed here was that the public was invited to give their input into the policy-making process and determine for itself how the ethical questions should be resolved. Without this, the anthropologist highlighted, it is debatable if the moratorium on organ transplants would have been lifted.

In summarizing her findings, Sleeboom-Faulkner further offered the view that what makes a difference as to whether a major public debate in Japan emerges or not has to do most with how this debate is couched by the dominant group. Specifically, had the issue of the moral status of the embryo been put in the hands of the public in the way the debate about brain death in the 1990s was, she argued, the scientific research in his area might have taken off and the scientific landscape might be different today. Furthermore, she hypothesized how even if the hESCR framework promulgated by the Koizumi Cabinet had been more endorsing than it actually was, in the absence of openness towards the public for debate and acknowledgement of the existing uneasiness about the utilization of embryos as a means for developing therapies, the outcome would have been exactly the same. The Prime Minister, she subtly suggested in conclusion, might well have made Japan, short of a full law, one of the first countries to permit hESCR, but without the public's anxiety about the destruction of embryos being acknowledged and assuages in the same fashion as its anxiety about cadaveric organ donation was recognized in the 1990s, and reflected in a parliamentary draft bill, the outcome of embryo donation and public funding for hESR coming to a stasis was predictable.

The theoretical appeal of her argument notwithstanding, a recourse needs to be made to how much tissue donation has actually taken place since the promulgation in 1997 of the Organ Transplantation Act. With regards to this, it is worth noting that the figures are not as high as expected or often portrayed. Indeed, although many assumed in the aftermath of the long-awaited 1997 Organ Donation Law that organ donations would palpably increase, or are

already doing so, a cursory glance at the data available for such surgeries reveals that this is hardly the case. The number of such surgeries in Japan continues to be staggeringly low compared with those of many other countries. There were merely 18.8 transplants per million people in 2021 in Japan, which is a far cry from the 126.8 in the US, for example. This is according to data from the United Network for Organ Sharing (UNOS), see <https://unos.org/data/>.

In real numbers this translates as 41,354 for the US and 76 in Japan (Japan Society for Transplantation 2022). And the reason why these surgeries are so few in Japan is the low number of organ donations: in Japan, organ donation took place in a mere 0.7% per one million deaths in 2013, for example, compared to 35.1% in Spain, 26% in the United States, 25.5% in France, 24.6% in Austria, and 20.8% in the United Kingdom. For data on the Japanese situation and how it compares with that of other developed countries see: The Nippon Foundation, August 2017, "Aiming for 1,000 Organ Transplants Annually in 5 Years", (<https://www.nippon-foundation.or.jp/en/news/articles/2017/20170801-21218.html>). Furthermore, it is worth mentioning that the numbers are stagnating from year to year, without any significant fluctuation.

Given these extremely low figures for Japan, the question arises as to why the opening of the debate and the promulgation of a law that reflects the variety of views expressed in the public about the issue not make that much of a difference? The way Sleeboom-Faulkner sees it, leaving it up to the bereaved (as specified by them in advance) or their family to decide whether they understand 'death' to mean 'brain death' or 'heart death' and whether to thus offer the organs in question in the case of the former having taken place for donation did make a difference. However, as the figures mentioned above suggest, there was hardly that much of a watershed moment for human organ transplantations in Japan with the promulgation of that law. The Japanese public seem to be still most reluctant to engage in tissue donation, and whilst there have been some such surgeries, a new stasis seems to have been reached. So, if conducting a proper debate with the Japanese public on this arguably equally contentious issue, of tissue donation at the other end of life's

spectrum, did not help resolve the stagnation, what reason is there to expect that consultation with the citizenry would make a difference in the case of donation of embryonic material?

With regards to cadaveric organ donation, it merits highlighting that it is mainly when a country changes its system to one whereby the burden is on the individual to specify that they do not wish their organs, or those of their family members, to be donated for transplantation—a system that is commonly known as an 'opt-out' one—that a palpable increase in such offerings can be observed. Indeed, judging that the issue of organ tissue donation is one whereby the majority in the public are simply not interested, as there is no immediate obvious benefit for them, most countries in Europe have now begun running an opt-out system. Notably, since this policy change happened, it has become noticeable how organ donation in Europe surged. What this evidence suggests for the case at hand of Japan's policymaking in the area of hESCR (and for that of cadaveric organ donation as well), is that instead of trying to hide from the public the details of the science, the establishment should give these details to the public in open, perhaps even introducing a system whereby embryos that have been stored for more than, say, 10 or 20 or 30 years would be presumed to have their creators' consent for donation to science, unless an explicit statement is made by the latter to the contrary. Would such a system not resolve the problem of tissue donation shortage in Japan in both cases? Of course, there will be those who object to the idea of hESCR for specific personal reasons. However, as with the policy of organ donation now adopted in many countries in Europe, there will be no barrier to people who object to their organs being taken as a default option to prevent this from happening—these people would be free to specify so in advance.

## Conclusion

Ultimately, the political maneuvering surrounding hESCR might well be something to which the statement once made by the American journalist James Reston that "All politics is based on the indifference of the majority" pertains." From what has been presented in this article at least, hESC politics certainly appears to be no exception to this dictum. But insofar as the machinations of the



Japanese establishment is concerned, rather than leaving itself to be pushed into a corner where it has to play a catch-me-if-you-can game *vis-à-vis* an uninterested public, it would seem more desirable that the Japanese scientific and political leadership, as the leadership in other countries as well, adopts the wide-spread European system for organ donation where the burden lies with members of the public to opt out of automatic embryonic tissue donation by default. This would mean that the indifference to hESCR by the majority in the public next translates in the *progression* of this science, as opposed to its demise, without there being a need for those seeking to advance this important science to play a game of cat and mouse.

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## Twilight years, gloom and the glow: Causes, challenges & ethics

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*"That time of year thou mayst in me behold  
When yellow leaves, or none, or few, do hang  
Upon those boughs which shake against the cold,  
Bare ruined choirs, where late the sweet birds sang."*  
- William Shakespeare (1)

### Abstract

Aging is the outcome of multiple causes. Essentially, it is the manifestation of molecular and cellular modifications leading to structural and functional decaying of the organism, rooted in genetic and epigenetic influences. Longer life span is a human success story reflecting victory over disease, debility and premature death, but population aging and the consequent demographic transition contemplates delicate balancing of diverse interests. Countries across the world are facing major socio-economic challenges because of the aging population. Responses range from very optimistic to very pessimistic as reflected in abundant literature on the subject. In this article after delineating the etiology of aging, its individual and social impacts, strategies to counteract the aging and the need to evolve appropriate measures to address the emerging challenges I deliberate on perspectives relating to ethical dimensions of the aging.

**Keywords:** Aging, retirement, debility, dependence, oxidation, senescence, telomere, stress, environment, equity, ethics

### Introduction

"Aging is the progressive accumulation of changes with time that are associated with or responsible for the ever-increasing susceptibility to disease and death which accompanies advancing age" (2) Causes range from the toxicity of free radicals to genetic predisposition. The cumulative and synergistic interaction of a myriad of factors make it difficult to signify a single predominant cause. Species specific longevity conserved for millions of years during evolution constitutes the single cardinal factor behind aging. In view of the fact that all mortals age and die the desire to defy

aging seems contrary to the order of nature. Even the stars age and die as black holes. Aging and death is thus an expression of cosmic consciousness. This intrinsicity notwithstanding, the victory over the aging is a cherished human pursuit becoming more captivating in today's world of advancing biotechnology and expanding face of medicine. The efforts range from genetic interventions to medications and spartan life styles. The expression "successful aging" is of wide import, carrying heterogeneous connotations depending on individual perceptions. A shorter life span may be more rewarding than a longer life if the individual feels happiness and satisfaction with life for the present and the past. The saga of fulfillment is not limited to longevity. Swami Vivekananda died at 39; Alexander the Great at 32.

The difference between the gloom and glow may be subjective but certain objective criteria can be discerned. The advancing years that are free from disease, dependence and discomfort, with intact serenity and self-confidence may be defined as a dignified and successful aging. However, longer life may not be a bliss for all as it is seldom without functional and cognitive impairment. Individuals with advanced age may lose the sense of purpose and may be the victims of financial insecurity, immobility, difficulty with daily

chores, lack of care, feeling of burden on the family members, inaccessibility to health care, lack of respect and loss of self-esteem. "While we are living longer, unfortunately, the world of employment and retirement has not evolved at the same pace. Many elderly people are able and more than willing to work past the standard retirement age, but the opportunities are not there" (3)

"According to World Population Prospects 2019 (United Nations, 2019), by 2050, 1 in 6 people in the world will be over the age of 65, up from 1 in 11 in 2019. All societies in the world are in the midst of this longevity revolution—some are at its early stages and some are more advanced. But all will pass through this extraordinary transition, in which the chance of surviving to age 65 rises from less than 50 per cent—as was the case in Sweden in the 1890s—to more than 90 per cent at present in countries with the highest life expectancy." (4) "Between 2015 and 2050, the proportion of

the world's population over 60 years will nearly double from 12% to 22%.” (5)

The subject of aging attracts a wide range of disciplines, including economics, demography, biotechnology, medicine, public health, sociology, bioethics, public policy and the law, among others. In this article while dealing with the etiology of aging, the emerging challenges, its individual and social impacts, global responses, Indian milieu and the strategies to delay the aging, I discuss its various ethical dimensions in a broader social context.

## 2. Etiology

Aging is the outcome of multiple causes leading to structural damage to molecules, cells and organs of an organism and the consequent functional and cognitive impairment. Essentially, it is the manifestation of molecular and cellular modifications leading to structural and functional decaying of the organism during the lifetime, rooted in genetic and epigenetic influences. The process depends on a variety of factors including hereditary, occupational and environmental. The DNA damage and cell senescence are the natural biological characteristics. There is now sufficient and diverse evidence to support that DNA damage plays a cardinal role in aging. This includes environmental/iatrogenic sources of genotoxic stress as well as spontaneous/endogenous genotoxic stress. The brain is particularly vulnerable to oxidative damage because of its high levels of polyunsaturated fatty acids and limited antioxidant activity. (6) Mitochondrial impairment and oxidative stress are widely considered to be central to the most common neurodegenerative movement disorder like Parkinson's Disease (PD) (7) Oxidation causes macromolecular damage of the DNA, lipids and proteins. “Cells are constantly exposed to a harmful environment throughout life. Increasing cell damage contributes to the dysfunction that characterizes the aging body”. (8)

However, the intrinsic factor that determines the length of life lies in the genes. “The enormous variation in the average lifespan in different species suggests that maximum lifetime is determined by the species-specific genotype” (9) Humans, being eukaryotes, possess telomeres which protect their terminal regions of chromosomal DNA from progressive

degradation. “Telomeres are DNA regions of variable length at the end of all chromosomes” (10) A correlation has been proposed between telomere shortening and somatic stem cell decline during aging (11) The enzyme telomerase adds specific DNA sequence repeats to the chromosome ends that are lost through cell division, thus restoring telomere length and delaying cell senescence, apoptosis, and death (12) “The fact that telomeres also shorten in vivo in humans with advancing age made a further compelling case for the idea that telomeres play a role in age-related processes.” (13) It has been estimated that in general, the average cell is able to divide 50 times before the telomere is used up (the Hayflick limit) (14) (15) “Because of their protective function for genomic DNA, telomeres appear to play an important role in the development and progression of many age-related diseases” (16) “Telomere syndrome manifestations that overlap with human age-related phenotypes” include, “hair graying, hair loss, nail ridging, periodontal disease, thrombocytopenia, decreased bone marrow cellularity, immune-senescence, gastrointestinal intraepithelial lymphocytosis, increased cancer risk, chemotherapeutic intolerance, emphysema, liver fibrosis, defective insulin secretion, insulin resistance and osteoporosis” (17)

The causes of aging like oxidative stress, glycation, telomere shortening, side reactions, mutations, aggregation of proteins, *etc.* lead to progressive structural damage inside the body which in turn leads to development of pathological conditions and, as a consequence, to death. (18) “Age changes can occur in only two fundamental ways: by a purposeful program driven by genes or by random, accidental events.” (19) . As regards the genes, “there is no direct evidence that genes drive age changes, their critical role in longevity determination is indisputable.” (20) “The common denominator that underlies all modern theories of biological aging is change in molecular structure and, hence, function”. (21) “It is a cornerstone of modern biology that a purposeful genetic program drives all biological processes that occur from the beginning of life to reproductive maturation.” (22) “The most compelling evidence for the belief that biological aging is also a random process is that everything in the universe changes or ages in

space-time without being driven by a purposeful program.” (23)

“Although some of the variations in older people’s health are genetic, most is due to people’s physical and social environments – including their homes, neighbourhoods, and communities, as well as their personal characteristics – such as their sex, ethnicity, or socioeconomic status” (24) “Beyond biological changes, ageing is often associated with other life transitions such as retirement, relocation to more appropriate housing and the death of friends and partners.” (25)

Genes indisputably play important role in aging. “The action of a single gene can have huge effects on how long a creature lives” (26) However, “Healthy aging and longevity in humans are modulated by a lucky combination of genetic and non-genetic factors” (27) “Large-scale genome-wide association studies have recently identified many loci that influence key human ageing traits, including lifespan. Multi-trait loci have been linked with several age-related diseases, suggesting shared ageing influences.” (28) “The application of powerful new human genetics technologies to the study of ageing has just begun. Unlike most other biological processes, the genetic factors that influence ageing may not be evolutionarily conserved because wild animals usually die from predation and infection, not ageing. Thus, animal models for ageing may have limited relevance to human ageing.” (29) “Despite decades of aging research, the role of genetic interactions ( $G \times G$ ) in heterogeneity of human lifespan, and in animal to human translation, remains not fully understood.” (30) “The study of longevity genes is a developing science. It is estimated that about 25 percent of the variation in human life span is determined by genetics, but which genes, and how they contribute to longevity, are not well understood.” (31)

Endocrinal factors too contribute in aging. Testosterone production and testicular function tend to decrease in aging men by 1–2% per year after the fifth decade. (32) (33) In particular, 25–30% of men > 60 years show low levels of serum testosterone. (34) Testosterone deficiency is linked to different signs and symptoms (such as reduced libido, reduced sexual functioning, decreases in mobility and energy) that could heavily affect the aging process and the quality of life. (35) (36) (37)

In sum, aging is the outcome of biological changes owing to genetic predisposition, life style, occupational hazards, exposure to wastes, diet, adverse environment, stress and morbidities, among other factors.

### 3. Challenges

“Population aging is a human success story, a reason to celebrate the triumph of public health, medical advancements, and economic and social development over diseases, injuries and early deaths that have limited human life spans throughout history.” (38) This achievement notwithstanding, “Opinions concerning the possibility of counteracting aging range from very optimistic to very pessimistic views and are described in numerous papers and comments on such papers.” (39) “Declining fertility and increasing longevity lead to rising numbers of older persons as well as a continuously growing share of older persons in the population.” (40) In certain parts of the world including China “Population aging has created an unprecedented global challenge” (41)

“In a few decades, the loss of health and life worldwide will be greater from noncommunicable or chronic diseases (e.g., cardiovascular disease, dementia and Alzheimer’s disease, cancer, arthritis, and diabetes) than from infectious diseases, childhood diseases, and accidents.” (42) “All countries face major challenges to ensure that their health and social systems are ready to make the most of this demographic shift.” (43) “Once key ageing genes and pathways are found, an individual’s genotype could predict the rate of overall health decline.” (44) The U.S. National Institute on Aging (NIA), has presented a snapshot of following challenges with regard to aging population:

- “The overall population is aging. For the first time in history, and probably for the rest human history, people age 65 and over will outnumber children under age 5.
- Life expectancy is increasing. Most countries, including developing countries, show a steady increase in longevity over time, which raises the question of how much further life expectancy will increase.

- The number of oldest old is rising. People age 85 and over are now the fastest growing portion of many national populations.
- Noncommunicable diseases are becoming a growing burden. Chronic noncommunicable diseases are now the major cause of death among older people in both more developed and less developed countries.
- Some populations will shrink in the next few decades. While world population is aging at an unprecedented rate, the total population in some countries is simultaneously declining.
- Family structures are changing. As people live longer and have fewer children, family structures are transformed, leaving older people with fewer options for care.
- Patterns of work and retirement are shifting. Shrinking ratios of workers to pensioners and people spending a larger portion of their lives in retirement increasingly strain existing health and pension systems.
- Social insurance systems are evolving. As social insurance expenditures escalate, an increasing number of countries are evaluating the sustainability of these systems.

New economic challenges are emerging. Population aging will have dramatic effects on social entitlement programs, labor supply, trade, and savings around the globe and may demand new fiscal approaches to accommodate a changing world" (45)

#### **4. Global responses:**

Positive global responses ought to reflect:

- i. Identification of biological and environmental factors behind unhealthy aging
- ii. Impact of aging population on the general population
- ii. Adequate resource allocation to meet specific requirements of the aging population
- iv. Equitable distribution of resources between the aged and the younger population.

Longer life span and the consequent demographic transition contemplates delicate balancing of diverse interests. "There is no typical older person. Some 80-year-olds have

physical and mental capacities similar to many 30-year-olds. Other people experience significant declines in capacities at much younger ages. A comprehensive public health response must address this wide range of older people's experiences and needs." (46) "Policies in this area include those aimed at eliminating age barriers in the formal labour market, promoting the recruitment of and flexible employment opportunities for older workers, as well as facilitating access to microcredit and providing other incentives for self-employment" (47) "The goal of human ageing research is not necessarily to extend lifespan, but instead to extend the healthy years of life". (48)

Meeting of health care and social service needs of the aging population calls for evolution of cost-effective policies in order to ensure that the younger groups do not get neglected. The State has to therefore ensure equity and equality in the distribution of resources. "The UN Decade of Healthy Aging (2021–2030) seeks to reduce health inequities and improve the lives of older people, their families and communities through collective action" (49) Older persons suffer from chronic diseases more frequently. "This, in turn, may result in an aging population with a significant burden of disability and dependency, leading to increased demands on the individual, the family, and the community, and increased utilization of health-care resources, as well as an increased economic and resource burden to society." (50)

In the USA, the Older Americans Act of 1965 was amended on March 25, 2020 reaffirming "the traditional American concept of the inherent dignity of the individual" and declaring that the older people of the Nation "are entitled to, and it is the joint and several duty and responsibility of the governments of the United States, of the several States and their political subdivisions, and of Indian tribes to assist" the "older people to secure equal opportunity to the full and free enjoyment" of a host of objectives as specified in the said Act, which include an adequate income, the best possible physical and mental health, suitable housing, opportunity for employment with no discriminatory personnel practices because of age, participation and contribution in meaningful activities, training and recreational opportunities, access to low-cost transportation, immediate benefit from proven research knowledge which can sustain

and improve health and happiness, freedom, independence, free exercise of individual initiative in planning and managing their own lives, and protection against abuse, neglect, and exploitation. (51)

Across the Atlantic, “elderly care in the UK is highly regulated, and care providers (whether residential, nursing homes, or care at home) are rigorously inspected to ensure clients are comfortable, safe, and healthy. In the case of live-in care, providers may be members of the United Kingdom Care Association (if they are members of the Live-In Care Hub, it is a requirement they are UKHCA members) and, if the provider manages carers and oversees service provision, they must be regulated by the Care Quality Commission” (52)

Jurisdictions are utilizing the advancing technology to optimize the use of public resources. “Today, technologies in gerontology and geriatrics that are powered by Artificial Intelligence (AI), the Internet, sensors and actuators have already been developed to help meet care needs, and these technologies can be useful in their capacities to support older people and caregivers in care provisions.” (53) “Japan, a super-aged country, has long been a forerunner in the adoption of technology in LTC” (54) “With one of the highest proportions of elderly people in the world, Japan is strengthening elder care. In 2000, the country implemented public long-term care insurance (LTCI), which includes preventive care, home visits, day services, short-stay services, residential services, and long-term care. LTC recognizes long-term care as a societal issue and provides affordable care financed by taxes and insurance premiums. Japan’s municipalities also have a community-based integrated care system, which aims to keep people with illnesses and disabilities living in their communities. It ensures that communities, rather than institutions, provide housing and support for daily living.” (55)

As per the reflections of the “Council of Europe’s report, Human rights of older persons and their comprehensive care, produced by the Committee on Social Affairs, Health and Sustainable Development,” the “older people continue to suffer from negative stereotypes that lead to discrimination, isolation and exclusion” (56)

In France, the Parliament enacted a law in 2015 in order to address the challenges of “population aging”. The main thrust of the law was an increase in the independence social allowance to combat inequality, and the introduction of a new tax to fund prevention and support regarding loss of autonomy (57). “France provides home help services to around 25% of elderly French residents, providing assistance to meet basic needs such as personal hygiene, transport, cleaning, and shopping. Services are available to all residents over the age of 60 who require them, but whether or not it’s covered by the state depends upon your income.” (58) As in other European countries, spending on the care of older people is increasing. From 1.40%, of the gross domestic product (GDP) in 2014 it is anticipated to rise to 2.07% by 2060. But according one report, “the healthcare system seems more fragmented in 2020 than in 2010, despite improvements in the culture of professional collaboration.” (59)

## 5. Indian milieu

In India a person above 60 years of age is considered as a senior citizen. As of 2019, over 139 million people living in India are aged over 60 and this proportion is expected to almost double to 19.5% in 2050 with 319 million people aged over 60. This means that every 1 in 5 Indians is likely to be a senior citizen. India is rated 130<sup>th</sup> out of 189 countries on the latest United Nations Human Development Index Ranking in 2018. (60) Many older people in India are not aware about their rights due to high occurrence of illiteracy and lack of alertness. “Surveys have found that one out of every six older persons living in urban areas in India aren't obtaining proper nutrition, one out of every three older persons does not obtain sufficient health care or medicine, and one out of every two older persons don't receive due respect or good conduct from family members or people in general.” (61)

Despite many government hospitals providing free medical care, the older persons find it difficult to tide over the cardiac problems, diabetes, kidney problems, blood pressure, joint problems and eye problems. Employment, housing, nutrition, transportation, routine health care continue to be the key concerns of life for the elderly. Meager interaction with

family and friends and poor social networking add to their woes.

The social and family structure in the Indian society is fast changing. "Hindu Epics (the *Ramayana* and the *Mahabharata*)—have addressed the issue of the ideal life course for an upper-caste man. In doing so, these ancient texts have discussed elaborately the cultural meanings attached to the process of aging and to old age—largely from a male perspective." (62) The ancient Indian model of a Hindu male dividing life's journey into four phases i.e., Student (Brahmacharya), Householder (Grahastha), Forest-dweller (Vanprastha) and Renouncer (Sannyasa), meant to maintain the discipline, peace and harmony in the family and society, has disappeared. That was, perhaps, the time when the life was chaste and livable in its full bloom. Globalization and cross cultural exchange has transformed the social pattern of aging. "The multifarious dimensions of ageing in India can sociologically be thought to be a series of transition from one set of social roles to another and such roles are structured by the social system" (63) "Institutionalization of elderly Indians seems to have been increasing with the aging of the twentieth century" (64) The life, now, is a continuous process of competition and struggle, full of rate race. It has tense and unpleasant moments with jobs that require hard work in order to compete with others for money, power and status, etc. The busy and demanding lifestyle, with repetitive work, leaves no time for relaxation leading to physical and mental stress. The problem is further aggravated in the case of elderly as in many cases the grownup children leave for jobs in faraway places leaving the aged parents alone.

The Indian Constitution, in part IV i.e., Directive Principles of State policy, contains specific provision about old age. Article 41 mandates that the State shall, within the limits of its economic capacity and development, make effective provision for securing right to work, to education and to public assistance in case of unemployment, old age, sickness and disablement, and in other cases of undeserved want. Article 47 asserts that the state must raise the level of nutrition and standard of living and to improve the public health of the people. These provisions entitle the elderly to live a healthy, peaceful, dignified life, with social,

economic and political support from the government. However, these articles being the part of the Directive Principles, are not enforceable through the Court.

There are certain statutory enactments protecting the aged against neglect and abandonment. The Hindu Adoption and Maintenance Act, 1956 empowers the elderly people with legal rights to claim maintenance from their children. Laws and rights under this Act can however be accessed by only Hindus.

Maintenance and Welfare of Parents and Senior Citizens Act, 2007 is a legislation, initiated by Ministry of Social Justice and Empowerment, Government of India to provide more effective provision for maintenance and welfare of parents and senior citizens. As per Section 2 (b) of the Act "maintenance" includes provision for food, clothing, residence and medical attendance and treatment. As per Section 4 (2) the "obligation of the children or relative, as the case may be, to maintain a senior citizen extends to the needs of such citizen so that senior citizen may lead a normal life." As per Section 19, the Government is under obligation to establish and maintain old age homes to provide necessary medical care and means of entertainment to the inhabitants of such homes. (65)

## 6. How to delay aging

Opinions concerning the possibility of counteracting aging range from very optimistic to very pessimistic views and are described in numerous papers and comments on such papers. (66) There is evidence that the consequences of genotoxic stress can be modulated through approaches like caloric restriction, NAD<sup>+</sup> supplementation, or ablating senescent cells. Reduction of oxidative DNA damage is thus associated with a slower rate of aging and increased lifespan.

"There is a large body of evidence that supports significant associations between telomere length and age-related diseases, such as CVD, T2DM, cancer, dementia, and osteoporosis." (67) The influences that enhance telomere length have been described as gender (longer telomeres being observed in females than in males), absence of psychological stress, nutritional adequacy, supply of micronutrients like vitamin A, D, C, E, B12, folate, and nicotinamide, minerals like magnesium, zinc,

and iron, and other dietary components, such as omega-3 fatty acid, polyphenols, and curcumin. The effects of vitamins on telomere homeostasis seem to be mediated by their antioxidative properties and the prevention of DNA damage. In addition to a healthy diet, regular physical activity also contributes to the preservation of telomere length via reducing sustained oxidative stress and inflammatory mechanisms. Furthermore, exercise has been shown to increase telomerase activity. Other lifestyle-related factors that potentially influence telomere length include smoking and alcohol consumption.

Regarding smoking, meta-analysis shows significantly shorter telomeres in ever smokers compared to those who never smoked. Taken together, there is good evidence that a healthy and active lifestyle with sufficient sleep and a low psychologic stress level contributes to the preservation of telomeres. Physical inactivity, nutritional deficits, overweight, stress, and smoking can accelerate telomere shortening and thus promote age-related diseases. (68) It has been found that caloric restriction slows aging and extends lifespan. Experiments in rodents and nonhuman primates caloric restriction has evoked positive responses on neurological, endocrine, reproductive, immunological, and antineoplastic functions, leading to longer life span (69) (70) The change in dietary regime may therefore delay the aging process.

Regardless of the particular cause of aging, the following can make a difference:

- Exercise - Studies have found that physical activity not only helps the heart and lung function well, but exercise lengthens telomeres.
- Healthy diet - A diet high in fruits and vegetables is associated with greater telomerase activity (in effect, less shortening of the telomeres in your cells). A diet high in omega-3-fatty acids is associated with longer telomeres but a diet high in omega-6-fatty acids is the opposite and associated with shorter telomeres.
- Intake of antioxidants
- Reduction of stress
- Avoidance of carcinogens
- Maintenance of a healthy weight - Not only is obesity linked with some of the

genetic mechanisms associated with aging noted above (such as increased shortening of telomeres), but repeated studies have found longevity benefits associated with caloric restriction.

- Sleep - a regular uninterrupted sleep for 6 - 8 hours
- Clean environment
- Company of family and friends
- Periodic medical check up to exclude the silent killers

## 7. Ethical dimensions

In a world where priorities in health range from safe drinking water to breast prosthesis, promises of biotechnology range from humanizing animals to creating new life forms, and the concerns of human rights range from the rights of the dead to the rights of the unborn, morality is on the crossroads and in many areas the concepts of right and wrong are not clear. In such a milieu, bioethics acts a source of clarity and direction. Bioethics originates from human virtues, which are innate and universal. Virtues breed values. Values breed morality. Morality defines the human conduct. Human conduct reflects as choices, pursuits and relationships

Aging is a journey of life from birth to death. The ethics of aging therefore emerges from a wide spectrum of perspectives. In addition to its genetic moorings, it embraces in its fold the expressions of individual urges and aspirations, scientific promise, human relationships, life styles, resource accessibility, culture, religion, politics, economics, history, law and State's regulatory power, among others. Despite these manifold influences, aging reflects an enduring feature of constant advancement in terms of longevity through the centuries. While deliberating the ethics of aging it is difficult to separate the discourse from philosophy. Let us imagine we win over the senile degeneration and circumvent death. What then will be the world like. It is difficult to answer this question precisely but what comes to mind is an earth saturated with human habitations, with hardly any empty space. One may argue that I am theorizing the future with imbued negativity. But, the theory needs to be intelligibly rebutted, with reason and farsightedness. The world is already in the grip of severe resource crunch and there is no scope for further human



invasion. Thus, while deliberating the ethics of aging we are confronted with following questions:

1. Should a maximum age limit be fixed?
2. Does one have a duty to die?
3. Out of the two i.e. healthy and terminally ill who should die first?
4. Should those who wish to live indefinitely be debarred from consuming earth's resources or at least restrictions be imposed on their consumptions?
5. In the event of resource scarcity, just enough for one person, whose interest should prevail, old or the young?
6. How to define old age in view of aging being a subjective manifestation, varying from individual to individual?
7. Can an upper age limit be fixed to declare a person as old?
8. Should a person's careless conduct leading to premature aging, disease and debility be a determinant while granting old age benefits?
9. What is the difference between age deceleration and human enhancement?
10. How to separate aging from the morbidities while deciding resource allocation?
11. What is the goal of addressing age related challenges? extending the life span or achieving a disease free life?

Some of the above questions may not have distinct answers. In the realm of ethics the discourse, at times, reaches a blind end as there are no answers to several questions: Why am I born? Why should I live? When should I die? At this point the debate turns philosophical. So, I leave it at that and move on to other ethical aspects of aging.

Depending on their priorities and resource availability, the issue of healthy aging and care of the elderly has been addressed by different jurisdictions by delineating welfare policies including benefits like pension, free medical care, housing, travel, entertainment and physical security etc. The laws have been enacted accordingly. But, there are voices that what is being done is not enough and the elderly deserve better care. This will go on unless competing interests of different stakeholders are adequately balanced. Those who aspire to age fruitfully will continue to expect more and more. In their point of view, it is a betrayal not to

recognize the services and contributions they made when they were young. They feel that, all along, they have lived not merely for themselves but also for the society and, as such, they possess an inherent right to care and support in their twilight years. A society exists and thrives on the values. No civilized society, therefore, can afford to divorce the values, unless it chooses to vanish. Aging, thus, opens a plethora of formidable moral issues and one has to navigate through a wide array of approaches.

As the debate goes on, let us examine the matter with a different perspective. Contemporary world order is founded on human dignity, scientific promise and the rule of law. Human dignity contemplates compassion and beneficence, scientific promise envisages victory over disease and debility, rule of law mandates equity and equality. In the context of aging, a bioethical prescription has to balance these moral diktats in an impartial manner. The ultimate answer lies in the people's will and efforts. Each individual is cast with a moral duty to adjust with the evening phase of life with objectivity, prudence and wisdom. This includes insight to reconcile with the inevitable. The expectations ought to be pragmatic, based on the following facts and circumstances:

- i. The resource constraint is an inevitable reality
- ii. One has to reinvent his/her approach towards the old age treating it as an expression of cosmic consciousness, drawing consolation that every object in the universe ages, even the stars turn in to black holes.
- iii. Equity contemplates everyone gets the share due to her/him. Those who have already consumed their share by living life should not enlarge their expectation at the cost of those who are yet to recoup their share. This means that younger in age are entitled to a higher share in the event of limited resources.
- iv. Persons should be conscious of the impending sequelae associated with aging and should adopt timely measures to minimize the impacts.
- v. The aged should voluntarily minimize their requirements
- vi. The younger individuals have a twofold obligation: (a) to ensure chaste living in order to minimize the old age complications, (b) to make strategic and economic planning to

tide over the old age, without being a burden on others.

vii. Resource optimization is the key to address the challenge. One has to moderate the expenditure on superfluous pursuits and gratuitous distractions, imparting transient pleasure

viii.. Life is precious and worthy of protection, regardless of age or longevity and each individual has an inalienable right to continue with his/her years as per her/his choice and volition by using her/his legitimate resources

ix. The world presents a ruthless panorama of inherent inequality. A person's inability to cope with her/his existence due to resource constraints cannot justify the imposition of curbs on others.

x. The unhealthy aging is not merely an individual affliction. It is a community challenge, with intricate social implications i.e., loss of productivity, disruption of families and diversification of resources

Various stakeholders involved in decelerated aging and longer life span are: the elderly, the younger one, and the State. The aged aspires for disease free aging and extra living care in view of subdued physical and mental faculties; the younger requires friendly and conducive environment for her/his development; the State as a regulator is obligated to generate the resources and has to balance the competing interests. All the three ought to act in a complimentary and synchronized manner. Misperception or slackness at any of the three levels will result in ethical miscarriage. In this context one may argue that the younger ones have a preferential claim as they have to cover a longer journey, the older ones have already consumed the resources and their existence is less fruitful to the society. "... one common concern about treatments for ageing is that they might extend the moribund stage at the end of life. Hospitals might become choked with chronically ill, elderly patients, languishing for years bedbound and miserable, at enormous cost to taxpayers." (71) Thus, in a situation like this, equity takes over the equality. However, a contrary view is also conceivable. "... delayed ageing could mean increases in social benefit and public healthcare costs, but that these would be far outweighed by economic gains as a result of a healthier workforce who remain

employed for longer and are given more time to save for retirement." (72) "Healthy aging will reduce the financial burden of care and delay the use of long term care (LTC), which involves a variety of services/activities designed to meet a person's health or personal care needs and to help them live as independently and safely as possible when they can no longer perform everyday activities on their own (World Health Organization, 2015)." (73) However, one needs to be cognizant that "the mortality risks, health status, type and level of activity, productivity and other socioeconomic characteristics of older persons have changed significantly in many parts of the world over the last century, and, in particular, in the last few decades" the "United Nations and most researchers have used measures and indicators of population ageing that are mostly or entirely based on people's chronological age, defining older persons as those aged 60 or 65 years or over." (74)

While dealing with ethics, one cannot be oblivious of the unusual emerging dimensions. Advancing biotechnology and burgeoning medical promise has redefined the human existence. People are dead but their bodies are alive. The industry's raw material are not only silicon and steel but they also include the human cells and tissues. The human beings have turned in to human material. Analysis and decoding of human cells and tissues and greater understanding of their composition and characteristics have reduced them to substances almost at par with any other organic compound, leading to obliteration of subject-object distinction. In such a marketized milieu the commercial intrusion may turn an extended life span into a physical asset imparting an added attraction to the aged not to leave this world.

Aging is already being commercialized. The medical world, comprising clinicians, pharmaceutical industry, diagnostic establishments, equipment and appliances manufacturers are busy advertising the remedies against old age manifestations. These costly interventions drastically add to the cost of old age management, with equivocal results. This also causes adverse impact on the general medical care due to diversification of resources. According to one report, "the typical elderly American receives far more medical services than those of younger ages. In 2010, average medical expenditures for an American

aged 65 or older were 2.6 times the national average. In the same year, people of 65 and older accounted for over one-third of US medical spending." In the same report it has also been found that "medical expenses more than double between ages 70 and 90, with most of the increase coming from nursing home spending." (75) According to NHE Fact Sheet, 2021 of the USA, "Per person personal health care spending for the 65 and older population was \$19,098 in 2014, over 5 times higher than spending per child (\$3,749) and almost 3 times the spending per working-age person (\$7,153)". (76)

In a world infested with poverty, hunger, illiteracy and disease with perpetual deprivation of basic necessities of life to vast majorities how far it is justified to channelize the resources for enhancing longevity of the population. It is better to ensure a healthy life span, albeit a shorter one, rather than prolonging it for gratuitous considerations. Life has to come to an end. Adding few more years, at the cost of denial to others, does not seem a dignified approach. Utopian goals ought not to haunt a health starved world. While deliberating ethics of age management one cannot ignore these dimensions.

In the ancient Indian way of life after a certain age a person used to enter the stage of Forest-dweller (Vanprastha) and Renouncer (Sannyasa), away from worldly affairs and was supposed to fend for himself, with no dependence on others and used to pass the remaining part of his life in the forest, isolated, divested of relationships and materialistic desires. The forest exile gradually tapered in to death. Thus the life's path, from the mythical fountain of youth to the ultimatum destination, was clearly defined. However, desire to continue is an intrinsic urge. Knowing fully well that death is an inevitable outcome one is not able to reconcile with this reality. The problems relating to aging are also rooted in this human fallibility. We want to live, live and live.

Aging is a natural trait and a cosmic attribute. Deceleration of aging may enter the realm of human enhancement, if pursued beyond a point. It is therefore imperative to differentiate between age deceleration and disease alleviation. The latter is a biological necessity while the former is a gratuitous disposition. An individual's penchant for longevity may, at times, reflect a personal proclivity, contrary to

larger social interest. "... the possibility of very large increases in lifespan—let us say, for argument's sake, to 150 years—is one that many find unnerving" (77) The ethical discourse in such a situation contemplates a broad array of parameters, traveling through an uneven terrain of concerns, in order to arrive at a definite and holistic destination. During this journey one needs to be continuously mindful that aging and death, being the expression of cosmic consciousness, are the universal realities. Science only discovers the existing. The nonexistent lies in the domain of realization. It is indescribable, unlike knowledge, and that is why "wisdom is not communicable". (78) (79) I feel the discourse is turning philosophical and I must stop at this point.

## 8. Conclusion

The process of aging refers to the decay of an organism's structure and function, in which molecular and cellular modifications can have various effects at the individual level over the course of a lifetime. The accumulation of molecular errors that compromise adult stem cell functions occurs because of genetic and epigenetic interactions and depends on hereditary, environmental, and stochastic factors. Genetics, cell senescence, oxidative damage and production of free radicals are responsible for aging.

The view is fast gaining ground that that lifespan can be extended dramatically and it is possible, and even achievable, to win over the hazards and ill consequences of aging, in the foreseeable future. However, this scientific optimism notwithstanding, unhealthy aging seems set to be a morbid reality for many as long as the poverty health nexus continues to exist as ever before. As per the UN estimates, "in 2020, a staggering 2.4 billion people, or above 30 per cent of the world's population, were moderately or severely food-insecure, lacking regular access to adequate food." (80)

A detailed account about aging strategies in different jurisdictions is not within the scope of this paper but the study reveals paucity of matching strategies across the world and the global panorama continues to be gloomy. The older people continue to suffer from negative stereotypes that lead to discrimination, isolation and exclusion" (81)

Aging involves cardinal perspectives of life and death. A healthy aging, free from disease and debility, leads to prolongation of life span, thereby delaying death. Although a blissful experience, it may have serious social repercussions in the nature of population growth, inaccessibility of resources, inequitable distribution, prejudice to younger generation, changes in lifestyles, altered family structures and human relationships. The ethics of aging therefore contemplates a holistic discourse in accordance with human virtues and social values. The challenges seem formidable as the resources are limited and cannot be stretched beyond a point. People's proclivities and the needs need to be equitably balanced. The concepts therefore call for great degree of scientific, social, religious and cultural integration.

Bioethics is an art of discovering ethical principles and paradigms in the face of competing and conflicting perspectives arising out of advancing biosciences, expanding face of medicine and emerging socio-economic imperatives. The discipline is rooted in intrinsic human virtues and evolving social values. In the context of aging, despite unanimity of respecting old age as a bliss and a source of wisdom and maturity the ethical conflict arises out of distribution and allocation of resources among different claimant in the society and several questions remain to be answered:

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## Land rights and land reforms to improve the socioeconomic status of indigenous communities in Peninsular Malaysia

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### Abstract

This paper's main argument is that the state has to safeguard Peninsular Malaysia's indigenous Orang Asli groups' customary land ownership and access rights in order to increase socioeconomic success. This can be accomplished by instituting land reforms. To protect their interests and rights as they adapt to modernization processes, the Orang Asli communities require constitutional, legislative, and institutional reforms. Despite the fact that the situation and condition of the Orang Asli in Peninsular Malaysia are historically, geographically, and politically distinct from other indigenous groups around the world, there is much to learn, particularly about preserving land for the benefit of the Orang Asli. We should consider accepting such challenges in order to integrate Orang Asli into our societies while preserving their distinct cultural and social identities. The plight of the Orang Asli appears to be rooted in issues of land governance and management. Land rights have a domino effect that affects the community's poverty level and displacement, which in turn affects the health and education of the Orang Asli. Members of mainstream society, both progressive and conservative, must now work together with Orang Asli to develop a set of reforms that will result in meaningful recognition of Orang Asli in Malaysia. A comprehensive reform package should include both practical and symbolic changes.

**Keywords:** Orang Asli, customary land ownership, land rights, land issues, Peninsular Malaysia

### Introduction

Malaysia has a long history of maintaining the wellbeing of its Orang Asli, or the indigenous peoples in Peninsular Malaysia. This effort actually predates the creation of Malaysia, as evidenced by the appointment of a field ethnographer in 1939 by the colonial government to serve as the "Protector of Aborigines" in the state of Perak, the enactment of the Aboriginal Peoples Ordinance 1954 (currently Article 134), and the creation of the Department of Orang Asli, also known as *Jabatan Orang Asli* (JOA) in Malay, which was tasked with the welfare and preservation of Orang Asli (Lye, 2001). The aforementioned



department is currently called the Department of Orang Asli Development, or *Jabatan Kemajuan Orang Asli* (JAKOA) in Malay. The social construction of indigeneity and its link to power in contemporary Peninsular Malaysia is strongly entrenched in colonial imaginations and persists under postcolonial governance (Nah 2006).

Thus, it came as no surprise when Malaysia became signatory to United Nations Declaration on the Rights of Indigenous peoples (UNDRIP) on 13<sup>th</sup> September 2007. Malaysia's Act and the role of JAKOA run parallel with the Declaration (United Nations, 2007), like conserving and upholding of Orang Asli tradition and heritage vis-a-vis right to cultural and ceremonial expression, right not to be forced assimilation or destruction of their culture; empowerment of Orang Asli through comprehensive development of human capital vis-à-vis rights to all levels and forms of education; declaration of aboriginal areas by State government vis-à-vis recognition of indigenous land, to name a few of the initiatives. Despite decades of investment in people and resources for Orang Asli development and welfare, they remain vulnerable, disadvantaged, poor, and marginalised, with only sporadic individual and group successes. This is particularly dire when other communities have improved by leaps and bounds.

Collectively, Orang Asli have not been lifted out of poverty threshold. According to the most recent data available, there were roughly 206,777 Orang Asli in Malaysia, or 0.6% of the total population. The three primary tribal groups in this heterogeneous culture are the Senoi, Negrito, and Proto-Malay, each of which is further subdivided into six sub-tribes. (Department of Orang Asli Development [JAKOA], 2020). Additional worldwide research (UNDP, 2016) shows that the poverty rate among Orang Asli is still high at 34%, significantly higher than the 0.6% national rate and among other communities. In contrast, the percentage of Bumiputera, Chinese, and Indians living in poverty was 0.8, 0.1, and 0.6, respectively. This situation further demonstrates that the Orang Asli community is economically, politically, health-wise, and educationally impoverished (Muhammad Fuad Abdullah et al., 2023).

Customary land rights may be the most significant issue impacting Orang Asli people. The federal government most recently and sensationally sued the Kelantan State government for failing to recognise customary land rights for the Temiar tribe and other indigenous communities in the state on January 14, 2019, following a string of lawsuits in which Orang Asli sued the State government over customary land rights (The Star Online, June 30, 2019). Land is a contentious issue because in Malaysia's constitution, land is a state matter and the role of Federal government is limited to promoting uniformity of law and policy and coordinating aspects relating to land law, administration and policy. Nevertheless, land is not exclusively a state matter and on occasions intervention from Federal government takes precedence. The call of former Chief Justice of Malaysia, Tan Sri Richard Malanjum to audit Malaysian laws on indigenous people whether in line with UN Declaration is timely and perhaps pivotal to change the fate of Orang Asli in the country ("Chief Justice calls", 2019).

Changes to strengthen and emulate best practices on matters regarding Orang Asli need not be viewed from a narrow perspective of benefiting Orang Asli only. Indeed, there is a vast potential such move will benefit all Malaysians. After all, extracting timber from their habitat will only create havoc to Orang Asli, it destroys the environment and the biodiversity of its inhabitants while benefiting only a small group of people and private profiteering; and bring short term financial gains to the state government over long term loss. The pristine, virgin jungles no longer stand. Establishing an Aboriginal region and enforcing it will give Orang Asli a firm foundation on which to grow and thrive. In turn, Orang Asli will become the custodians of Malaysia's prime jungle and national heritage, protecting biodiversity, flora and fauna, and securing critical water supplies for future use.

Notably, earlier studies (Edo, 2004; Carey, 1976) suggest that Orang Asli tribal groups view land as a mark of honour and seniority in the region. They are therefore emotionally and symbolically connected to the land. Given that their ancestors' remains are buried in the soil, they assert that they have a spiritual bond with the ground. For the Orang Asli, access rights to customary land ownership entail a complicated

web of obligations to their departed ancestors who had tilled and farmed the land, as well as to their own family members. Thus, the purpose of this document analysis study is to explain the relationship between indigenous land reforms and the institutional, legislative, and constitutional changes made to Orang Asli customary land ownership.

### Current Dilemmas of Orang Asli

The conceptual framework that follows (Figure 1) describes the primary issue facing Orang Asli communities as being the high percentage of poverty, with land issues being the primary cause.

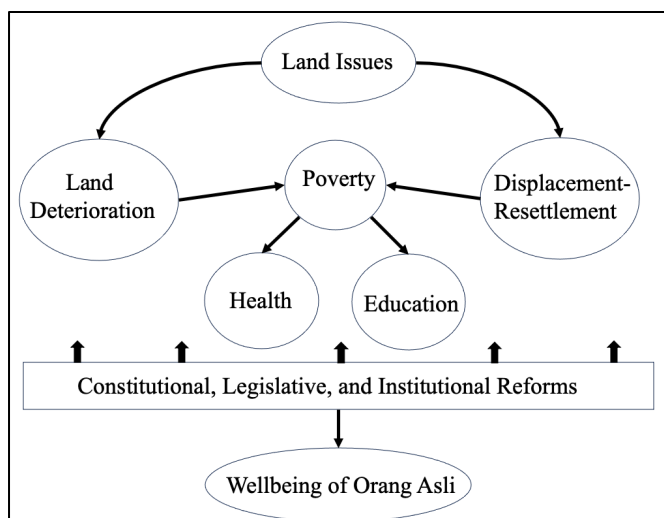


Figure 1: Conceptual framework on land issues and their impact on the wellbeing of Orang Asli

#### 1. Land Issues=

The importance of landownership in reducing poverty cannot be over-emphasized, a fact that is acknowledged by the whole wide world. Land, besides providing shelter, it also provides means of livelihood for the indigenous communities. Forest land is like a supermarket in modern days (Sarah Sabaratnam, NST Online, 15 May 2005), supply Orang Asli with water, vegetables, fruits, fish and meat, firewood, building materials, medicinal plants, resources for the spiritual practice and all other necessities. Their mode of livelihood in hunting-fishing-gathering activity together with subsistence cultivation sustained Orang Asli for generations in the past. It is no wonder that Orang Asli placed enormous attachment and respect to the forest land.

#### (a) Development-Induced Displacement and Resettlement

It is depicted in Figure 1, that land issues faced by Orang Asli communities in the Peninsular Malaysia came in 2 aspects. One, displacement and resettlement, where the Orang Asli communities were displaced from their original settlement or from their customary land. Later, they were resettled in nearby or in a new location. Second, land deterioration, whereby settlement area and their roaming area suffered or degraded due to depletion of resources, living conditions worsens as a result of outside interference and disruptions (Jamalunlaili Abdullah, 2016).

As early as 1951, the British colonial government had started to resettle Orang Asli, moving them away from their dwellings into new settlements which were hastily prepared camps in order to cut-off food supplies and intelligence to the communist insurgents during the emergency period (Polunin 1953). Again, in the mid-1970s where the communists were operating from South Thailand, resettlement was planned to defuse the security threat. However, this time a comprehensive plan was prepared with objective to provide security as well as to improve the indigenous communities' socio-economic condition for their eventual integration and assimilation to the mainstream society tasked by then JHEOA (*Jabatan Hal Ehwal Orang Asli* - Department of Orang Asli Affairs) (Khor, 1994).

Thus, Orang Asli communities has been subjected to numerous displacement and resettlement programs, sometimes due to security reasons, development projects like construction of Temenggor Dam, highway projects, land development programs to raise the socio-economic level of Orang Asli or combinations of these factors. The resettlements could be carried out in-situ (in original Orang Asli settlement), regroupment scheme within or in the vicinity of original Orang Asli settlement areas or away from the original Orang Asli settlement such as Felda scheme. The Federal Land Development Authority (Felda) is a Malaysian government agency that was established to coordinate the resettlement of rural poor into newly developed regions (settlements or schemes) as well as the organisation of smallholder farms farming cash crops (Lim, 1997).

Table 1: Total residential and cultivated land of Orang Asli between 2006 and 2014

S/N	Land Status	Hectares (2006)	Hectares (2014)	Percentage 2006 (%)	Percentage 2014 (%)
1	Land gazette as Aboriginal reserve land	19,303.43	19,774.22	13.94	20.80
2	Land approved, not gazette as Aboriginal reserve land	28,932.28		20.89	
3	Land requested, awaiting approval as Aboriginal reserve land	79,715.53	75,181.40	57.57	79.08
4	Land not approved as Aboriginal reserve land (Inappropriate)	9,873.04		7.13	
5	Property of indigenous person	644.17	115.53	0.47	0.12
	Total	138,468.45	95,071.15	100	100

Source: JAKOA (2006)

Table 2: Average monthly household income of three Orang Asli villages

Characteristics	No. of Household	Main Economic Activity	Average Monthly Household Income (RM)	Incidence of Poverty
Remote Village (Musuh)	26	Subsistence farming, collection of forest produce	RM 139 (USD 37 in 1990)	100 %
Regroupment Scheme (Bukit Serok)	135	Oil palm cultivation, wage earning, collection of forest produce	RM 530 (USD 140 in 1990)	68 %
Resettlement Scheme (Felda Keratong 3)	27	Oil palm cultivation, wage earning	RM 661 (USD 174 in 1990)	31 %
Rural Village in Malaysia		Mainly agriculture	RM 1,167 (USD 309 in 1990)	22 % in 1990

Source: Lim (1997)

Table 3: Monthly Income of Residence in Sungai Benua, Hulu Terengganu

Income	No. of Family	Percentage (%)
< RM 580 (< USD 145 in 2018)	2	4
RM 581 – RM 870 (USD 145 – 218 in 2018)	46	92
>RM 871 (> USD 218)	2	4
Total	50	100

Source Jamalunlaili Abdullah et al. (2018)

The process of resettlements may be carried out voluntarily or by compulsion. Whatever scheme they are or mode of resettlement, the Orang Asli were not given the land tenure on the land provided in the scheme, nor is the surrounding area or their roaming area given as communal land. These lands are under various stages of State Authority's land administrative process whether they are: gazetted, approved,

or un-approved as Orang Asli reserve land. Nevertheless, Orang Asli living in the resettlement are all deemed as tenant at will under the Aboriginal Peoples Act 1954 (Act 134), no land title may be alienated (Zainal Abidin and Seow, 2013). They are not the landowners!

Even though there is some semblance of protection for these Orang Asli land under the

Malaysian Constitution's clause (85)(5), where Aboriginal reserve land is federal land and any conversion by State Authority for other uses is subject to consent by the Federal government, State Authority shortchanges this by simply not gazetting the land as Aboriginal reserve land, as shown in Table 1 (Zainal Abidin and Seow, 2013).

According to Table 1, as of 2006 and 2014, the majority of Orang Asli residential and cultivated land (86% and 79%) has not been designated or gazetted as Aboriginal reserve land despite decades of waiting. This suggests that the approval process for gazette customary land grants to Orang Asli communities in Peninsular Malaysia has not improved significantly. However, the Malaysian government and JAKOA both believe that land ownership is critical to lifting Orang Asli out of poverty and raising their living standards to those of Malaysia's mainstream society. Over the last few years, there has been positive news about Orang Asli villages that have been or will be gazetted. Some of the examples include Bukit Baja Indigenous Village in Selangor (Chen, 2024, July 9), Pos Lanai Indigenous Village in Pahang (Kampung Pos Lanao, 2023, April 10), and Gua Musang Indigenous Village in Kelantan (Paya Linda Yahya, 2023, September 18).

#### (b) Land Deterioration

In addition to land issues caused by displacement and resettlement as shown in Figure 1, Orang Asli likewise struggled with the destruction of their customary land. The deterioration of Orang Asli forest land was mostly caused by the issuance of logging and mining licenses, as well as large-scale plantation development projects on or near Orang Asli customary land regions. Encroachment of Orang Asli customary territory has been ongoing for decades. These encroachments were not highlighted prominently due to Orang Asli ignorance or lack of understanding of basic rights and property, ignorance of customary land boundaries, a lack of support from government agencies, and logging companies' strong-arm tactics and aggressive stance (Abdullah Khoso and Yew, 2015).

The aforementioned development initiatives negatively impacted the lifestyle of the Orang Asli since they were implemented without careful consideration for the

environment that affects them. It results in the loss of natural resources and ecosystems, the depletion of wildlife populations, the destruction of fishing sites as a result of siltation, sedimentation, and pollution, the reduction or destruction of jungle produce, and the destruction of forest and riverine resources. Additionally, the water supplies that the Orang Asli uses for drinking, bathing, and washing are contaminated or polluted, and the river has become muddied. If a nearby alternative water source is not found, major health issues will arise.

According to Khor (1994), the socioeconomic statuses of the Orang Asli Regroupment Scheme's inhabitants remain low, despite the fact that several of the communities have been in situ for more than a decade. Logging and mining activities licensed by State government, near to Orang Asli settlements especially in the upstream area will bring deterioration to Orang Asli livelihood, where jungle devoid of trees will deprive Orang Asli of food source and contaminate their water supply. As such, through displacement and deterioration of Orang Asli habitat, it had made Orang Asli poorer economically, which in turn will affect their communities' diet and nutrition and subsequently the education of the Orang Asli children. As a result, the Aboriginal Peoples Act (1954) is no longer considered appropriate in modern Malaysia, as it cannot give security, certainty of occupation, or ownership of land (Hooker, 1970). Again, land issues such as displacement and resettlement, as well as the destruction of forest land, have contributed to the Orang Asli's poverty.

## 2. Poverty

The primary goals of resettlement are to eradicate poverty, improve the socioeconomic standing of Orang Asli villages, and facilitate their integration or assimilation into mainstream society (Khor, 1994). Regroupment or Resettlement schemes and land development programs were used to bring Orang Asli into the production of cash crops, which produce more consistent and higher incomes. These crops included rubber, oil palm, cocoa, fruit trees, and vegetables.

Lim (1997) examined the impact of the Resettlement Scheme on the Orang Asli communities' ability to improve their standard

of living during the early stages of the schemes' development. Table 2 compares the household incomes of three Orang Asli villages, namely Bukit Serok under the Regroupment Scheme, Felda Keratong 3 under the Felda Scheme, and the isolated village of Musuh - to the average rural Malaysian household income. Notably, the settlements of Felda Keratong 3 and Bukit Serok were judged to be effective resettlement efforts.

According to a newer study by Jamalunlaili Abdullah et al. (2018), the Orang Asli Resettlement Scheme in Sungai Berua, Hulu Trengganu, was established in 1977 after the original customary land was cleared for the construction of the Kenyir Hydroelectric Dam. After 40 years of resettlement, 92 percent of settlers were satisfied with the effort, earning between RM 581 and 870 (USD 145 - 218). The monthly earnings of settlers in 2018 are shown in Table 3. There has been no discernible improvement in the financial standing of the indigenous populations living in their resettlements, which were located away from their customary territory, when compared to the monthly income earned by settlers in 1990 (Table 2). Apparently, there is no significant difference in income level between these two periods, according to Lim (1997) and Jamulunlaili et al. (2018), and the settlers remain poor. Thus, resettlements have largely failed to move Orang Asli out of poverty.

### 3. Education

Resettlement of Orang Asli ostensibly is only the first step that the government undertook to eradicate poverty among Orang Asli communities. Acquiring education is necessary to help transform social and economic opportunities of Orang Asli, thus, administrators and educators alike focus efforts on improving school facilities and teachers training program for Orang Asli, as drawn up in the Malaysian Education Blueprint (Ministry of Education, 2013). This blueprint was formulated with a view of the current dismal results of Orang Asli, only 30 percent of Orang Asli students complete secondary school, less than half of the national average of 72 percent, and only 61 percent of Orang Asli students pass the core subjects in the Primary School national examinations (Ministry of Education, 2013). This trend of high dropout

rates among Orang Asli students continues, as current data shows that the Ministry of Education Malaysia announced in November 2021 that 42.29 percent of Orang Asli students did not complete their schooling up to Form Five in 2021 and 58.62 percent in 2020 (Orang Asli, 2022, December 29).

According to Wong and Abdillah (2018), various factors lead to poor educational success among Orang Asli children, with poverty being one of the most significant. For example, because of poverty, Orang Asli households continue to struggle to put food on the table every day; this need for food will always take precedence over children's education. Children from Orang Asli communities must assist in the search for jungle products for consumption or sale. In addition, the absence of transportation will lead to low enrolment and poor attendance at school, and the low income of the indigenous villages will preclude Orang Asli children from enrolling in any pre-school program or paying tuition. Lack of utilities, such as electricity, would also prevent Orang Asli children from completing their homework and reviewing their lectures, which will ultimately lead to a high dropout rate and subpar performance on public exams (Wong and Abdillah, 2018).

The Malaysian government's policy towards Orang Asli has always been paternalistic, and the previous Department of Orang Asli (*Jabatan Orang Asli* [JOA]) was established under the Aboriginal Peoples Act (1954) with the same powers and functions to dictate the development and welfare of Orang Asli. It was also the "Emergency Period" where security was the chief concern for the government of the day, thus, the Director General of JOA was given tremendous power and control over Orang Asli affairs, such as authority to create Orang Asli settlements, reserves, and areas, control of entry, appointment of headmen, registration of Orang Asli, over methods of evidencing and recording rights of occupancy, planting of specific products, felling of jungle, taking of jungle produces, taking of animals and birds (Hooker, 1970). Undoubtedly, certain policies such as these are no longer regarded as democratic and might not be effective in the modern world. An increased focus on consultation and participation is necessary. Orang Asli should have greater autonomy over their lives and be

held responsible for any outcomes that result from their involvement and collective decision-making. Gaining education and knowledge should fortify their will to pursue self-determination in their work and way of life and boost their self-assurance in social interactions with members of the mainstream culture.

#### **4. Health**

Orang Asli's health is also a cause for concern. According to Phua (2015), the infant mortality rate among Orang Asli is 51.7 per thousand live births, compared to 8.9 for the Malaysian population. The life expectancy of Orang Asli is only 53 years, but the Malaysian population is 73 years (Rusaslina Idrus, 2011). Current indigenous health status backed such facts on health deficiency. In the Che Wong tribe (Pahang), for instance, it has been discovered that 25.0% of women and 13.8% of males are underweight among adult Orang Asli. Poverty, inconsistent eating habits, improper cultural values, ignorance of nutrition, inadequate cleanliness, and increased helminthic infestations are some of the factors contributing to this (Tay et al., 2022).

On the health issue, an additional case from the recent spates of deaths among the Batek people was highlighted in all major newspapers; these were identified as simple measles outbreaks, but disease had spread due to malnutrition and a failure to provide vaccine protection (Azura Abas, 2019). Even if such events are isolated, Orang Asli's overall health is far from excellent. Malnutrition, poisoning of water resources, and other factors have made life for Orang Asli in the distant interior is extremely difficult.

Worm infestation is fairly frequent; in Karim's (1995) study, 48 percent of Orang Asli males and 73 percent of females had worm infestation. The condition can cause abdominal pain, diarrhoea, exhaustion, and weight loss. According to a research by Yusof (2007), 40 percent of the Orang Asli males in the sample had symptoms of nutritional inadequacy, such as iodine and vitamin A deficiencies, which can lead to goitre and anaemia in Orang Asli. Due to chronic medical conditions like worm infestation and malnutrition brought on by poor income, Orang Asli communities are more susceptible to infections like meningitis, which

has been linked to recent incidents of Batek death (Azura Abas, 2019).

Because of their low economic level, Orang Asli have poor health conditions, which can be linked to inadequate and poor quality nutritional consumption. These findings are supported by the studies listed above. Undoubtedly, income has a significant impact on nutritional quality, particularly for Orang Asli with underprivileged backgrounds. According to Khor (1994), the Orang Asli living in the interior who followed their traditional lifestyle prior to resettlement appeared to have a good nutritional status. This was most likely because of their dietary habits, which addressed the issue of adequate nutrition by consuming a wide variety of foods found in forest land. Due to resettlement, Orang Asli villages continue to suffer from malnutrition as a result of poverty.

#### **Methodology**

This study is based on document analysis (Bowen, 2009) as a form of qualitative research where secondary sources related to the issues faced by the Orang Asli were reviewed. The keywords used for searching the required secondary full-text literature written and published in English and uploaded online include "Orang Asli", "land rights", "land reforms", "legal reforms", "constitutional reforms" and "institutional reforms". According to Yin (1994), document analysis as a research method, produces rich description of a single phenomenon. Furthermore, as Merriam (1988: 118) mentioned, 'Documents of all types can help the researcher uncover meaning, develop understanding, and discover insights relevant to the research problem'.

In this study, many sources and document contents were reviewed in light of the difficulty encountered by Orang Asli communities in Peninsular Malaysia, as well as the study's research purpose and conceptual framework. To establish the reliability, accuracy, and representativeness of the selected documents, document analysis is a method of examining documents in order to generate empirical knowledge and understanding. During the procedure, the researchers seek for objectivity and sensitivity while maintaining a balance between the two (Bowen 2009).

## Discussion

### ***Comparable Orang Asli and Maori policies in New Zealand***

Previously, the Maori in New Zealand faced similar dilemmas as the Orang Asli in Peninsular Malaysia, but thanks to some constitutional, legislative, and institutional reforms, they have been able to embark on a new path free of major obstacles and work towards securing a brighter future for themselves and integration into mainstream society in New Zealand (Muhamad Sayuti Hassan et al., 2023).

Maori people differ from Orang Asli communities in Peninsular Malaysia in that they entered into the Treaty of Waitangi with the Crown (Te Puni Kōkiri, 12 November 2018), which gave them important standing and rights in New Zealand. This resulted in the development of institutional structures such as reserved parliamentary seats, which recognise and give Maori a voice in New Zealand's political system. Comparable constitutional measures, including allocating a small number of reserved seats in parliament, would allow over 200,000 Orang Asli a representational voice in Malaysian politics and a voice in parliament.

In terms of land matters, we should make sure that the constitutional rights of Orang Asli and their customary land rights are acknowledged by all state governments. The Ture Whenua Maori Act 1993 (Te Puni Kōkiri, 12 November 2018) was enacted in New Zealand to regulate Maori land. This land is divided into three categories: Maori customary land, which is owned by customary or traditional systems but lacks a certificate of title; Maori general land, which is land that passes out of Maori ownership; and Maori freehold land, which makes up over 98% of Maori land. Sixty-four percent of Maori land is controlled by Maori incorporations and trusts.

It is proposed that the current Aboriginal Peoples Act 1954 be amended to ensure that indigenous groups in Peninsular Malaysia have greater control over their socioeconomic circumstances. It is prudent to use the new Torrens land registration system in New Zealand for giving titles to customary lands, which is a legally binding system that cannot be contested or cancelled unless through appropriate legislation.

### ***Constitutional, Legislative and Institutional Reforms***

A national policy on Orang Asli must be developed, including Orang Asli customary land rights. This will avoid the displacement of Orang Asli and the degradation of their habitats. Large-scale relocation of Orang Asli should be discouraged, while small-scale (few families) relocation should be promoted for the goal of centralising Orang Asli and providing social amenities to their communities. Most studies on Orang Asli customary lands are concerned about the indigenous customary land rights awarded, which should be permanent and irrevocable. Ideally, such customary lands should correspond to national goals such as water catchment areas and virgin jungle preservation.

In terms of institutional reforms, Orang Asli should play a more active role in self-determination by forming an Orang Asli Council that will collaborate with JAKOA. For this, the Orang Asli Council might turn to a number of Maori Council rules and processes (Booth 1963).

According to the study's document analysis findings, education has an important role in enabling indigenous peoples to overcome poverty. Thus, redesigning the curriculum and teaching methods to better suit Orang Asli, particularly at the primary school level, is critical. There were good approaches, such as the 'beh LINUS' teaching and learning model at The National Orang Asli Primarily School Sungai Berua in Kuala Berang, where Orang Asli children were first taught about sanitation and the nutritional value of breakfast in the morning, followed by music and leisure activities (e.g. congkak, guli, and educational video watching) in between regular lessons. Later, students were taught the government school syllabus, and the school referred to this stage of learning as "beh LINUS". This 'beh LINUS' strategy has been shown to boost student attendance and increase their chances of continuing their secondary school education. Teachers assigned to Orang Asli schools are urged to take special training classes to better understand Orang Asli children and communities that gel (Yew et al., 2021).

The "beh LINUS" paradigm mentioned above applies the concept of learning via play to the classroom, making it a priority in the process of teaching and learning. Children



naturally learn via play, which can be used as a mediator to provide the most effective learning outcomes for the indigenous students. Games can be included into educational sessions to increase children's motivation, interest in, and attempts to finish the content being presented. This is because using games to teach students will speed up their learning and make them more enjoyable. In actuality, playing strategies can keep youngsters from getting bored and help them get over their fear of the things they are learning.

## Conclusion

Many of the publications discussed in this document analysis study were published in the late 1990s and early 2000s. Nonetheless, the Orang Asli community's socioeconomic and health situation have not improved significantly. Finally, this paper contends that Orang Asli communities require constitutional, legislative, and institutional reforms to ensure a good "start" towards achieving a high level of social wellbeing and contributing to the betterment of Orang Asli families and communities. It may take several generations of dedicated effort to fully integrate into Malaysian society.

It is anticipated that the pace will start out slowly and erratically but, with perseverance and determination, it will gradually pick up speed and reach its objective. Orang Asli and mainstream society must now collaborate, progressive and conservative alike, to develop a package of reforms that would result in real recognition of Orang Asli in Malaysia. The ideal reform package will be both practical and symbolic, and it will have the support of Malaysians.

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