ADDRESSING GENETIC DISCRIMINATION IN THE MEDICAL TAKAFUL SYSTEM IN MALAYSIA

Shaikh Mohd Saifuddeen & Muhammad Hisyam Mohamad

Abstract

The progress achieved by man in the field of medicine and biotechnology thus far is indeed commendable as it has paved the way to a better quality of life. For instance, the advancement in genetic technology has made early detection of genetic disorder possible. Similarly, the development in gene therapy techniques has raised chance in alleviating and curing genetically-linked diseases which the hope in treatment of such diseases was slim in the past. Nonetheless, in spite of beneficial effects the progress in this field may bring to us especially in regard to human health, they may not be seen as good from another angle. One of the adverse effects of the proliferation of genetic technology is the potential misuse of genetic information by health insurance companies. Thus, this article seeks to analyse the issue of genetic screening and its potential impacts on the medical takaful system (Islamic medical insurance) in Malaysia. The article will also try to explain that in the absence of acceptable solutions for certain predicaments within the existing frameworks, Islam offers its own approach that is practical and ultimately leads toward inculcating universal values such as cooperation and brotherhood in members of society.

Keywords: biotechnology, gene therapy, genetics, genetic discrimination, takaful.
Introduction

For its believers, Islam is a complete way of life. The complete way of life of a Muslim is governed by the Islamic Shariah (or the Islamic law). The Islamic Shariah does not aim to cast unnecessary restrictions on the life of a Muslim. Neither is it meant to make life as a Muslim difficult. Instead, the Islamic Shariah is promulgated with good intentions and objectives which aim to protect the benefits of the individual and that of the community. It is also aimed at improving and enhancing the quality of human life on earth.

Advancement in the areas of medicine, pharmacy, and biotechnology has resulted in methods that help to enhance the quality of life. For example, medical devices and equipment are now available to visualise conception and help monitor the foetus well-being. Gene therapy is a strong possibility in the near future which can theoretically be used to alleviate genetically-linked diseases. These are some of the developments that must be analysed by the Muslims in the most positive manner. In other words, progress and development of modern biotechnology and medicine have now made genetic screening a possibility.

In view of this reality, the Muslim community must realise that these medical and biotechnological advancements will affect them, not only in terms of healthcare, but also on their everyday activities or muamalah. One of the instruments of muamalah used by Muslims is the Islamic medical insurance. As such, this article will look at the impacts of genetic
screening and genetic disclosure on the Islamic medical insurance with special reference to Malaysia.

**Genetic Diseases and Screening**

In this modern age, infectious diseases are more controllable. However, one of the major concerns of modern man is genetic diseases. A group of untreatable genetic disorders which include genetic defects and congenital malformations have surfaced since the last millennium. Genetic diseases include a wide variety of syndromes which include “chromosomal, multifactorial, mitochondrial, and somatic cell genetic disorders.” With the advancements made in medicine, these genetic diseases can be screened and diagnosed using various diagnostics such as chromosomal analysis, pedigree analysis, clinical examination, biochemical analysis, DNA analysis, histopathology, imaging and other forms of investigation.

Genetic diseases can be categorised into single gene disorders, chromosomal disorders, multifactorial disorders, somatic cell mutation, and mitochondrial disorders. Single gene disorders follows a particular clear manner of inheritance in the family pedigree, but is rare. Genetic diseases under this category include Thalassemia, sickle cell disease, cystic fibrosis, haemophilia, and neurofibromatosis.

The second category, namely chromosomal disorders, include diseases such as Down syndrome, Klinefelter syndrome, Turner syndrome, and Trisomy of chromosome 13,18.

Multifactorial disorders is a category of genetic diseases which is common and affect a high percentage of the population, with many are inborn defects while others appear in later life. Genetic diseases under this category include congenital malformation, Harelip, Cleft palate, diabetes mellitus, hypertension and cardiovascular diseases. The other two categories of genetic diseases are somatic cell mutation (which include malignancies and aging process changes), and mitochondrial disorders (for instance hereditary blindness and labour optic atrophy).

Hence, efforts have been directed towards newborn screening and carrier detection for varieties of genetic disorders. These efforts are aimed at better

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understanding of genetics in health and disease conditions and achieving control and prevention. The hope is that this will decrease the suffering of the affected individual, the psychosocial and financial burdens caused by these disorders.

Prevention, including protection against gene or chromosomal damage arising from environmental or occupational exposure to mutagens or teratogens\(^2\) as well as avoidance of conception of a carrier foetus is considered to be effective. The use of donor gametes, or pre-natal diagnosis followed by abortion, are limited alternatives. The recent advances and developments in molecular biology and biomedical research lead to better understanding of the genes and their defects and enabled various options such as preclinical diagnosis, carrier detection, and preimplantation diagnosis.

In essence, we note that Islam puts the emphasis on prevention rather than cure. Genetic screening, thus, can be looked at as a form of prevention. However, there are many ethical considerations that need to be looked at, as well as understanding the impacts of the information obtained through genetic screening on the Islamic medical insurance.

**Communicating Results of Genetic Screening**

There are many ethical issues that need to be addressed vis-à-vis genetic screening. However, one of the main concerns is the considerations in communicating the results of genetic screening. Traditionally, a patient’s right to confidentiality is treated with the utmost care by doctors and hospitals. Any form of disclosure of a patient’s information would require informed consent, either from the patient or in certain cases, from the patient’s family. The requirement for informed consent is essential, except in very rare circumstances, such as “to avert a serious harm to identifiable third parties, to prevent the spread of serious and contagious diseases, or for other overriding social considerations.”\(^3\)


Without a doubt, the result of genetic screening would be of interest to various parties. Aside from family members, other parties who may want to know the results of genetic screening are employers (current or future) and insurers, as this information is pertinent in “calculations for business decisions.” One of the ethical debates on this matter is whether or not these parties (employers and insurers) should be regarded as a major stakeholder or only a minor stakeholder with regard to the patient’s genetic information obtained from the screening procedure. Whose decision is it to inform the employer and the insurer – is it the patient’s decision or is it the doctor’s decision? Is it then ethically acceptable for the patient who has knowledge of his genetic information to withhold said information from his employer and insurer? In the United States of America, it is strongly emphasised that “explicit informed consent” from the patient is needed before such information is given to employers and insurers. This is given great emphasis in order to avoid “unintended social or economic injury.”

The ethical questions raised need to be deliberated upon extensively. These ethical issues have been discussed at great length in many developed nations. However, since genetic screening is not an option that many people can afford in developing and underdeveloped nations, these debates have yet to gain any prominence. In Malaysia, for example, while genetic screening is available, it is not a diagnosis treatment that people would take without a strong reason as the cost involved is high. Medical screening for employment and insurance purposes is necessary, but the screening does not include the need for genetic screening. In view of this, the implications that genetic screening has on employment and insurance has yet to be explored fully in Malaysia. As such, this article will attempt to look at the issue of whether there exists genetic discrimination in the Islamic insurance system or takaful in Malaysia.

**Takaful: A Brief Overview**

The word “takaful” is derived from the Arabic verb “takafala” which literally means “joint guarantee” or “guaranteeing each other.” In the contemporary practice of Islamic finance, the term refers to a Shariah-compliant alternative to insurance which built

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4 American Medical Association, “Opinion 2.137.”
5 American Medical Association, “Opinion 2.137.”
upon the principles of pure cooperation (ta’awun), joint-indemnity and mutual responsibility enshrined by the Quran and the Hadith.\(^6\)

In a *takaful* scheme, the notion of mutual help and mutual indemnity are put into motion when a group of people contribute a certain amount of money to a common fund – on a basis of donation (*tabarru’*) – which is then used to indemnify any members in the group against any loss or damage he or she may incur during the contractual period.\(^7\)

In view of the complexity of the process of managing a common pool and its related procedural operation requirements, the participants give a mandate to a *takaful* operator to manage the fund on their behalf.

A *takaful* company is neither a seller of protection nor an indemnity provider. It is merely an operator who is given a mandate to run a *takaful* operation on behalf of the participants. The tasks of the operator – among others – are to manage the risk and investment business of the *takaful* members.\(^8\) For the service rendered, it receives some fee-based compensation or a share of the profit derived from investment and underwriting surplus.

Such arrangement distinguishes *takaful* operation setup from its conventional insurance counterpart. In insurance, the element of mutuality is absent as the contract is a pure sale contract whereby the insurer sells the protection and indemnity for a money consideration called the premium.

**Risk and Undertaking Process in *Takaful***

Notwithstanding the distinction in their underlying principles, both *takaful* and insurance operation fundamentally deal with the same concern, i.e. risks. In fact, risks

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are at the heart of insurance and takaful.\textsuperscript{9} There are several types of risks faced by the takaful industry. However, the most critical risk is the underwriting risk which the operators assume through takaful contracts they underwrite.

The sustainability of any takaful business relies heavily on the quality of underwriting activities. It is a type of filtering process between favourable and unfavourable risks which enables a takaful operator to control the quality of takaful applications thus minimising the problem of adverse selection.

Poor underwriting practices not only result in financial risk to the takaful operator, but also pose threat to takaful participants’ interest as it can cause the risk fund – which is used to pay claims – to run into deficit.

\textbf{Health Status Disclosure}

In order to minimize adverse selection problem, takaful operators have made it a prerequisite that all applicants – especially those who want to participate in family takaful schemes such as medical takaful – to disclose a range of details into account, but not limited to their personal information and health status. In fact, the applicants are also required to declare their spouse’s medical (if any) status as well as their family medical history.

In developed societies, there is a growing concern among the public of the need to fully disclose relevant details including genetic information and the individual’s family medical history to insurance companies. Their concern relates mainly to the practice of the insurance industry whereby the latter use the applicant’s genetic information as a selection criterion in granting insurance coverage and as a determinant of the insurance premium.\textsuperscript{10}

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The practice which solely based on future or perceived genetic risk has two implications for the people with hereditary diseases in their family. First, they may be denied insurance coverage. Second, if the insurance company accepts their application, they may have to pay the premium at an exorbitant rate.

**Law Governing Genetic Information**

In many European countries, life insurance is seen as a basic socioeconomic good. The practice is therefore deemed as discrimination which impedes people from getting a basic need – an insurance coverage. In an effort to protect people's right to affordable insurance, most European countries and the United State of America have enacted laws safeguarding citizens against aspects of abuse of genetic information by insurers (and employers). One of those laws is the USA Genetic Information Non-Discrimination Act (GINA) of 2008. The act among other prohibits insurers from using genetic information to their advantage to deny coverage to a healthy individual or to charge him higher insurance premium on the basis of predisposition evidence alone, i.e. family history.

**Genetic Discrimination in Malaysia**

Unlike the United States of America and most European countries which outlaw genetic discrimination by insurance companies, the Malaysian government has yet to reach a position on such laws. There are several factors contributing to this state of affair. In Malaysia where the awareness on bioethics is still relatively low, the issue of genetic discrimination is not a matter of much interest to the general public. As a matter a fact, the National Bioethics Council – a national body entrusted with the task of mainstreaming bioethics and disseminating information on bioethical issues among

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people from all walk of life including scientists – had only been established in May 22, 2012.\textsuperscript{14}

Being newly established, it means the council has some preliminary administrative tasks to work. These include organising committee meetings and identifying relevant bioethics issues to be addressed. This also means that it will take some time before the council can come out with something concrete on genetic discrimination.

Based on the current situation, it can be inferred that Malaysians are vulnerable to manipulation from takaful/insurance industries that could possibly increase the premium or deny the coverage on a mere perceived genetic risk of the potential insureds.

Currently, there are 12 takaful companies operating in Malaysia\textsuperscript{15} which offer a range of medical takaful products (besides other general and family takaful products) to the public. A comparison among medical takaful proposal of three takaful operators namely Syarikat Takaful Malaysia Berhad, Etiqa Takaful and Great Eastern Takaful shows that there exists a standard industry practice to ask potential insureds – in addition to their own medical conditions and lifestyles – to declare their family health history.

**Genetic Discrimination: A Justifiable Practice in Takaful?**

While voluminous studies show that inheritance is a key risk factor for most diseases like diabetes, heart disease, cancer, mental disorder, etc.; in the case of medical takaful in Malaysia, a healthy individual with family medical history would not face denial of coverage. Besides, he would also need to pay the same contribution amount (premium) as the one without inherited genetic traits.

Nevertheless, this does not imply that no discrimination exists in the medical takaful contract. Under family takaful schemes of which the medical takaful product


\textsuperscript{15} See the Malaysian central bank’s website: \url{www.bnm.gov.my} for the full list of the takaful operators.
belongs to; all contributions received from participants (insureds) are segregated into two funds namely Participants’ Risk Account (PRA) and Participants Account (PA).

The PRA is a mutual fund which is a result of a collective donation (tabbaru’) of all policyholders. In the event of any claim warranted under takaful policies, the compensation to indemnify the insured will be made from this fund. On the contrary, the PA is an exclusive property of the individual participating in a takaful contract. It is meant for savings and investment. Upon maturity of the policy or in the case of claim, the total amount of contributions paid by the participant together with the profits from the investment will be returned to him.\textsuperscript{16}

For a standard application, i.e. a healthy applicant without genetic susceptibility, a substantial amount of the takaful contribution will be channelled into the PA while a small portion will go into the PRA. However, the takaful operator will increase his PRA portion if make a declaration that he is genetically predisposed to hereditary illnesses such as cancer, heart disease, diabetes etc.

Here, the participant with perceived genetic risk is technically discriminated against because he has to contribute more to the PRA compared to other takaful members. The question is: Is it a justifiable discrimination?

To answer this question we must relook at the underwriting process which is the very first step that all prospective clients must go through before they are eligible for the takaful coverage. It is plainly a discriminative process in nature – yet it is an industrial practice – incorporating two essential elements namely selection and classification. In the process, the degree of risk of an applicant will be assessed and he will be assigned to a group of participant of the same expected loss probabilities. The assessment among others requires the participant to disclose all material facts or the matter affecting takaful policy.\textsuperscript{17}

The information furnished will be used by the underwriter in his decision making process as to acceptance of the risk and to ensuring equal treatment and fairness in the contribution rate that each participant pays proportionately to the risk presented to the company. Hence in takaful contract – similar to its counterpart

\textsuperscript{16} See Alhabshi et al., \textit{Takaful}. See also Frenz and Soulhi. \textit{Takaful & Retakaful}.

\textsuperscript{17} Mohd Ma’sum Billah, \textit{Applied Takaful and Modern Insurance} 3\textsuperscript{rd} ed. (Petaling Jaya: Sweet & Maxwell Asia, 2007), 195.
insurance – it would be better if the insured could disclose more information to the company as it would enhance the actuarial fairness of the scheme.\textsuperscript{18}

In Islam, Muslims are required to observe and uphold fairness and justice in their day-to-day activities. As a matter of fact, Islam gives due emphasis to its importance as many verses in the Quran expressly state the command to do justice. One of the most often cited is the following from Surah al-Nahl:

\begin{quote}
Surely Allah enjoins the doing of justice and the doing of good (to others) and the giving to the kindred, and he forbids indecency and evil and rebellion; he admonishes you that you may be mindful. (16:90)
\end{quote}

The above commandment also covers fairness in all contractual dealings that an individual enters into. Here in the case of a healthy \textit{takaful} applicant with genetic risk status who has to contribute more to the PRA, he is not being discriminated against. Yet, he is actually doing justice to the rest of members of the group as he pays proportionately according to the risk he brings to the common pool.

In fact, a full disclosure made by the client to the \textit{takaful} operator is deemed commendable by the Islamic law. This is because a \textit{takaful} policy is a contract of utmost good faith.\textsuperscript{19} Any party enter into such a contract must therefore disclose the truth of the facts or it may become null and void in the event of non-disclosure of any relevant information relating to the policy.

The justification of the above argument is based on a Hadith which the Prophet Muhammad said to the effect that: “Muslims are bound by their conditions except the condition which prohibits the lawful one or the one which permits the prohibited one” (Sunan al-Tirmizi, Kitab al-Ahkam, No. 17).

In view of the nature of the \textit{takaful} policy which is based upon mutual assistance and the spirit of Islamic brotherhood, the insertion of full disclosure principle in a \textit{takaful} contract is obviously in line with the emphasis stressed by the aforementioned Hadith. Therefore, all policyholders are bound upon all terms and conditions set forth in the contract.


\textsuperscript{19} Ma’sum Billah, \textit{Applied Takaful}.
Subsequently, the non-disclosure could not only nullify a *takaful* policy but it could even result a much condemned act in Islam that is to earn through unlawful means. Regarding this, it is stated in the Quran to the effect that:

*O you who believe! Do not devour your property among yourselves falsely, except that it be trading by your mutual consent...* (4:29)

When a potential insured submits his *takaful* proposal without observing the principle of utmost good faith, the *takaful* operator could end up with adverse selection and he will be grouped with those of the same risk category. He could eventually deprive the other members of the same pool of their welfare by submitting a claim to the *takaful* company for the losses incurred as per *takaful* policy whereas in actual fact the contract may not be recognised by the Shariah for he has already breached the contract.

**Addressing the Dilemma**

As mentioned earlier, a *takaful* operator – like its conventional counterpart – is very particular when it comes to risk selection whereby all new applications must go through a comprehensive underwriting process which then provides justification for the company whether to accept, postpone or reject the application.

By nature, the process is obviously discriminatory but deemed acceptable and approved by Shariah as a standard practice for *takaful* business. In addition to the underwriting process, there is no law in Malaysia law protecting consumers against misuse of their genetic information by *takaful* or insurance companies.

These two elements i.e. the underwriting process and the absence of law concerning genetic discrimination, could establish a strong premise that for the time being, consumers in Malaysia could not totally rely on the existing *takaful* infrastructure for their medical coverage. They should not rule out the possibility of denial of coverage as it had already been experienced by western consumers.

Another point that could add weight to this argument is the way in which the concept of *takaful* is now operationalised. It is worth noting that the concept of modern *takaful* is actually based upon several Islamic and pre-Islamic notions of risk management that were free from element of commercialism. If we examine the
doctrines of ‘aqilah, qasamah and dhaman\textsuperscript{20} practised by the Muslims during the early age of Islam, they are purely centred on the spirit of co-operation, protection and mutual responsibility.

However looking into the current industry practice, we may realise that these noble spirits seem cease to exist as most of takaful providers are operating as a private limited company. The initial takaful models tend to be driven by Shariah-up decision rather than business-down decision.\textsuperscript{21} The new takaful operators generally take a business view of takaful. Although it is not wrong to switch from non-profit to commercial status, there is a danger that the spirit of takaful may be lost or severely diluted in the process. In other words, the change in the implementation of takaful practice will in some ways erode the spirit of mutuality and co-operative principles on which the concept was originally established.

The notions of takaful seem not to be comparable with the modus operandi of a corporation or private limited company.\textsuperscript{22} In most of the cases, motivation for profits and the pursuit for financial gains supersede all other implications. This is also an early indication that the industry has now being captured by the ideology of capitalism. Even now, the influence of capitalism in the industry is apparent as takaful products have become more costly and less accessible to those in need.

**Searching for Solutions Beyond the Takaful Framework**

The solution for healthcare exclusion may not be found within the operational framework of the existing takaful business models. Nevertheless there is a need to address the problem and seek a feasible solution that would work in the interest of this marginalised group of people.

In Islam, there are several social protection mechanisms which could be resorted to in fulfilling the task that the corporate sectors may deem it is not economically viable to work on. One of those mechanisms is waqf.

\textsuperscript{20} Ahmad Mohamed Ibrahim, “Philosophy of Islamic Insurance.”
Waqf is a unique voluntary financial mechanism for charity in Islam. If correctly managed and executed, waqf would not only generate a continuous reward for the waqif even after his death, but also contribute to social and economic well-being of the Muslim community.

Throughout the Muslim history, the waqf institution has been recognised as a financial instrument that helped government to reduce its public expenditure. There are numerous historical evidences supporting this statement. One of those is the success story of cash waqf implementation during the Ottoman Empire era which had impressed economists with a “no cost to the government” on the public amenities provided to members of the community. Such amenities include education, healthcare, municipalities, etc.

The potential of waqf institution in improving the quality of life of the Muslim remains relevant even today as it used to be in the past. In area of healthcare, the innovativeness of corporate waqf pioneered by the Malaysian Johor Corporation or JCorp is another proof that waqf is a dynamic economic instrument of Islam which its practicality remains valid regardless of timeframe and where the concept is applied or who applies it.

The JCorp waqf programme was established on August 3, 2006 when the corporation endowed RM200 million worth of its share in three of its public listed subsidiaries namely Kulim (Malaysia) Berhad, KPJ Healthcare Berhad and Johor Land Berhad to a waqf programme. Waqaf An-Nur Corporation Berhad is a company established under limited guarantee by JCorp, entrusted with managing all equity PLC shares transferred by JCorp to Waqaf.

In order to ensure the corpus of waqf remains intact, only the dividend earned from these shares is channelled to the intended beneficiaries/purposes. One of them is to finance the operation of 18 Waqaf An-Nur Clinics (KWAN) and Waqaf An-Nur Hospitals (HWAN) in several states in Malaysia. In term of percentage, the allocation channelled stands at 12.5% on a firm commitment basis.

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The main objective of KWAN and HWAN is to provide healthcare services to the deserving patients at the nominal charge of RM5 including medicine. Besides, HWAN and KWAN also offer dialysis treatment at a subsidised priced for qualified patients. It also co-operates with Baitulmal, SOCSO (the Malaysian Social Security Organization) and other welfare agencies to enable patients to receive free treatment at HWAN or KWAN. As at December 31, 2012, a total of 869,488 patients received their treatment from KWAN of whom 6.9% of them were non-Muslim patients.  

Conclusion

Even though the advancement in science and technology can sometimes produce negative externalities on human welfare, the truth is, it must be seen a broader and critical perspective. This is because in most of the cases the benefits outbalance the negative aspects.

However, in addressing the requirement on the disclosure of genetic information on takaful applicants by takaful companies and the issue of genetic discrimination in their underwriting process, it seems that both are inevitable and necessary. This is to safeguard the welfare of takaful participants who are in the same risk pool as well as to protect the interest of other takaful’s stakeholders.

In view of this situation, perhaps, the initiative of JCorp could be replicated by other corporations and philanthropic foundations. It is hoped that by emulating this exemplary deed, the access to good healthcare for all members of society – regardless of their genetic status – will improve as more charity based clinics and hospitals will be built throughout the country.

References


