Stakeholders’ Intention to Adopt Gene Therapy in Malaysia: Effects of Age, Education, and Religion

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Abstract
Gene therapy is a medical procedure in which new genetic material (genes) are introduced into the human body to treat disorders or diseases. Although the technology holds huge promises for improving human health, it is also one of the most controversial topics in modern medicine. Therefore, research into stakeholders’ intention to adopt gene therapy and its predicting factors is important to influence the successful implementation of this new therapeutic tool. The objective of this article is to assess the effect of background variables such as age, gender, and religion on behavioral intention to adopt gene therapy and its predicting factors. A validated questionnaire was distributed to 421 adult respondents (aged 18 years and older) comprised of two groups: health care providers (n = 221) and patients (n = 200). The results of the study suggest that the Malaysian stakeholders involved in the study were cautious although they perceived gene therapy as having high benefits, and were highly accepting from a religious perspective. This was reflected in their high intention to adopt gene therapy. At the same time however, they acknowledged the existence of moderate risks. One-way MANOVA analysis detected significant differences in terms of perceived benefits across ages, and behavioral intention across educational level. However, no significant differences were detected in the comparison of all factors across religions. This study serves as a useful baseline for scientists, government regulators, policy makers, and political leaders for understanding Malaysian acceptance of gene therapy and should encourage more research in the future.

Keywords
gene therapy, behavioral intention, predictors, age, education, religion, Malaysia

Introduction
Gene therapy (also called human gene transfer) is a medical procedure in which new genetic materials are introduced into the human body to treat disorders or diseases (Deng et al., 2017). The treatment aims to alter, replace, or modify abnormal genes. Gene therapy can be used to treat many disorders such as cystic fibrosis, anemia, sickle-cell diseases, Alzheimer’s, arthritis, cancers, and cardiovascular diseases (Health-Tourism, 2018). Initially, gene therapy was used as a strategy to treat monogenic diseases, but the application has expanded into many other conditions such as cancer, infectious diseases, and primary immunodeficiency (Deng et al., 2017). The first report on the success of gene therapy was published in 1990 when medical scientists reported the successful treatment of a 4-year-old child suffering from adenosine deaminase deficiency (ADA) and another condition called Leber’s congenital amaurosis (Bainbridge et al., 2008; Rakoczy & Larsson, 2014). Subsequently, this application was shown to have great potential for the treatment of a variety of genetic and non-genetic conditions (Robillard et al., 2014).

According to Ginn et al. (2018), the statistical data on the total number of gene therapy clinical trials up to November 2017, a total of 2,597 clinical trials have been carried out worldwide, with the United States in the forefront, accounting for most of the trials (64.9%), followed by the Europe (23.2%), Asia (6.5%), Australasia (1.3%), Africa (0.2%), and multicity trials (3.9%). Deng et al. (2017) reported that the gene therapy trials are mostly focused on cancer research (64.6%),...
followed by monogenetic diseases (10.5%), infectious diseases (7.4%) and cardiovascular diseases (7.2%). On the contrary, China was the first country in the world to approve the first gene therapy-based product (Gendicine) for clinical use (Peng, 2005). It has also been reported that Chinese scientists were the first to use cells modified using the CRISPR-Cas9 gene editing technique in a clinical trial (Cyranoski, 2016). This inspiring news shows that China is becoming a leader in this field, particularly in the industrialization of gene therapy. However, in Malaysia, gene therapy is still in its infancy. However, research on human genetics and experimenting using CRISPR technology is in progress, and more research should be carried out in other developing countries.

Research into public attitudes toward gene therapy or gene editing has mostly been carried out in Western countries (Wang et al., 2017). In Europe, there has been an increase in support for gene therapy—up to 63% as compared with 54% in 2005—but some other aspects of medical genetics are more likely to generate controversy such as religiosity and ethical concerns (Allum et al., 2014). In general, the public approves the use of gene therapy when it has the purpose of improving individual health, as opposed to intelligence or appearance (Blendon et al., 2016). Rapid developments in clinical gene therapy have caused a growing number of concerns in the scientific community and in the general public alike (Blendon et al., 2016). Balancing the benefits and harm associated with using this new therapeutic tool are most commonly discussed (Wang et al., 2017). As previous studies vary widely in geographic location and time, it would be interesting to conduct a study to identify the Malaysian stakeholders’ intention, and to consider the predicting factors associated with adopting this new therapeutic tool as there has been no previous study regarding the attitudes, perceptions, and acceptance of gene therapy in Malaysia. Therefore, the objective of this article is to assess the effect of background variables such as age, gender, and religion on behavioral intention to adopt gene therapy and its predicting factors. Age, education, and religion were selected as the demographic variables to be considered in this study because many previous studies have reported that these factors influence people’s acceptance of gene technology. Age difference has been reported to significantly influence people’s attitudes toward gene editing (Critchley et al., 2019; Strong et al., 2017), while education levels were also found to be a significant factor in evaluating public support of genetic modification (Wang et al., 2017; Weisberg et al., 2017). Meanwhile, many past studies have indicated that religion is a factor which is particularly likely to influence respondents’ acceptance of genome editing (McCaughhey et al., 2016; Scheufele et al., 2017; Wang et al., 2017).

**Research Methods**

**Survey Data Collection**

The research data were collected by a survey on 421 adult respondents (aged 18 years and above) in three established government hospitals which provide medical genetics services in the Klang Valley region of Malaysia, from June to September 2017 (Table 1). The Klang Valley has been chosen as the targeted area in this study because it is the center of Malaysia’s economic, social, and biotechnology industry. In addition, the people who reside in this area meet the requirements in terms of the diverse backgrounds needed for this study. The stratified random sampling method was used to categorize the targeted population into two stakeholder groups: health care providers and patients. These groups were chosen as the study population, because they are considered to be the main players in terms of the future adoption and rejection of gene therapy, and their attitudes have a major impact on the successful research and implementation of the technology. The health care providers consisted of medical doctors, geneticists, pharmacists, a nurse, medical science officers, and nutritionists. They were combined into one group as their interests are the same, that is, the provision of health care. Meanwhile, patients were those who had received medical treatment at a genetics clinic, or their family members.

Because this study was quantitative in nature, the minimum sample size required for each form of statistical analysis was considered. Cohen (2013) suggested that, for the age and education category, a minimum of 52 respondents per sample group is needed to obtain the power of 0.80 ($f = 0.25$, $p = .05$, $u = 2$), and a minimum total of 44 per sample group is needed for the religion category ($f = 0.25$, $p = .05$, $u = 3$). On the contrary, Krejcie and Morgan (1970) recommended that for any population size beyond 5,000, a sample size of 400 would be adequate (Krejcie & Morgan, 1970). Consequently, the two stakeholder groups were allocated almost equal samples: health care providers ($n = 221$) and patients ($n = 200$).

Prior to data collection, a complete set of the questionnaire used in this study was distributed to the respondents by a number of trained enumerators who had a background in genetics and biotechnology. Before the study was conducted, a brief introduction regarding medical genetics and gene therapy was presented to the respondents and they were

| Table 1. Characteristics of Respondents ($n = 421$). |
|---|---|---|
| **Background** | **$n$** | **%** |
| **Age** | | |
| 18–25 | 65 | 15.4 |
| 26–40 | 278 | 66.0 |
| ≥41 | 78 | 18.5 |
| **Education** | | |
| Secondary schools | 37 | 8.8 |
| Pre-university | 90 | 21.4 |
| University | 294 | 69.8 |
| **Religion** | | |
| Muslim | 283 | 67.2 |
| Buddhist | 47 | 11.2 |
| Hindu | 62 | 14.7 |
| Christian | 29 | 6.9 |
allowed to ask any questions to ensure that they understood the purpose of the study.

**Survey Instruments**

One of the multi-dimensional instruments used in this study—the questionnaire—was made up of 21 items that were constructed based on earlier work (Amin et al., 2013, 2017, 2018). It explored the respondents’ characteristics, specific attitudes, and behavioral intention toward gene therapy technology. The specific attitude variables were perceived benefits, perceived risks (Amin et al., 2013, 2017, 2018; Gaskell et al., 2010), religious acceptance (Hashim et al., 2017; Kelley, 1995), and behavioral intention (Pin, 2009). The questionnaires were presented in Malay and English. Both versions were back translated and validated by certified translators. All items were measured using a 7-point Likert-type scale. According to Wu and Leung (2017), an increased number of Likert-type scale points will result in a closer approach to the underlying distribution, and hence normality and interval scales.

**Validity and Reliability of the Instrument**

The content and face validity of the questionnaire was examined by experts in the areas of consumer behavior, measurement, and ethical issues in gene technology. Prior to the actual study, a pilot study was conducted to test the strength of the items used, and to determine the validity and the reliability of the research instrument. The Cronbach’s alpha reliability coefficient value shown in the study was higher than the .7 set by Heale and Twycross (2015) and Mugenda and Mugenda (2003) (Table 2). Factor analysis was carried out to assess the validity of all the factors (Table 2). Hair et al. (2010) suggested that standardized loadings of all factors greater than 0.5 indicated a good level of validity, while the corrected item-total correlations for all items in each dimension were also considered good (above .5; Table 2).

**Data Analysis**

Data analysis was carried out using the Statistical Package for Social Sciences (SPSS®) version 24.0 for Windows. One-way MANOVA was used to test the effects of age, education, and religion on the intention and its predicting factors with regard to the adoption of gene therapy.

**Results**

**Socio-Demographic Characteristics**

Table 1 provides the socio-demographic background of the study respondents ($n = 421$). From the results obtained, the majority of the respondents were female (59.1%) and aged 26 to 40 years (72.4%). Most respondents reported having a high school degree or greater (69.9%), as intermediate and basic education levels were 21.4% and 8.8%, respectively. The majority of the respondents were Malay (62.2%),
followed by Chinese (17.3%), Indian (15.2%), and other Bumiputras (5.2%). In terms of religion, 67.2% of the total respondents were Muslim, 14.3% were Hindu, 11.2% were Buddhist, 6.7% were Christian, and others made up 0.7%.

**Test on the Homogeneity of Covariance Matrices**

The stakeholders’ intention to adopt gene therapy across age, education, and religion were analyzed based on four dimensions: perceived benefits, perceived risks, religious acceptance, and behavioral intention. Box’s M test was performed on the data, first to determine the homogeneity covariance matrices, as MANOVA makes an assumption that covariance matrices are equal within the group. From Table 3, we can see that the data meet the assumption of equal covariance matrices. Following MANOVA, multivariate analysis revealed that the perceived benefit was shown to have significant differences across age ($p < .05$), while the behavioral intention variable showed significant differences across education ($p < .05$; Table 4). However, one-way MANOVA could not detect any significant differences in terms of religion (Table 4).

**Perceived Benefits**

Overall, the Malaysian stakeholders perceived gene therapy as being highly beneficial, with a mean score above the midpoint of 4.0 (with a mean score of 5.55; Table 4). Respondents aged ≥ 41 were shown to have the highest level of perceived benefits toward gene therapy (with a mean score of 5.75) as compared with those of other ages. One-way MANOVA detected a significant difference in the perceived benefits, and the post hoc test again confirmed that significant differences in benefits rating exist between respondents aged ≥ 41 and 18 to 25 years (Table 4). Meanwhile, the respondents who hold a tertiary education level (university) qualification was assessed to have the highest level of perceived benefits (with a mean score of 5.63) compared with respondents with other education qualifications. Comparing across religions, Muslims judged the benefits of gene therapy the highest (with a mean score of 5.62) as compared with other religious denominations (Table 4). However, one-way MANOVA could not detect significant differences in the perceived benefits across education and religion (Table 4).

**Perceived Risks**

The overall stakeholders’ risk perception with regard to gene therapy were considered to be moderate (with a mean score of 3.75; Table 4). Respondents aged 18 to 25 years considered gene therapy to possess the highest level of risk (with a mean score of 3.90) as compared with other age groups (with a mean score 3.63 and 3.72, respectively; Table 4). Meanwhile, respondents with pre-university and university education rated higher in terms of level of risk related to gene therapy (with a mean score of 3.70 and 3.69, respectively) compared with secondary school (with a mean score 3.58; Table 4). Comparing across religions, Hindu respondents were shown to perceive gene therapy as being more risky (with a mean score of 3.79) as compared with other beliefs, and Muslims have been shown to account for the lowest level of perceived risk toward gene therapy (with a mean score of 3.65; Table 4). However, the multivariate analysis could not detect any significant differences in the risk ratings of gene therapy for different ages, levels of education, and religions (Table 4).

**Religious Acceptance**

Overall, the stakeholders strongly indicated that gene therapy technology is highly acceptable in terms of their religion and their customs (with a mean score of 5.35; Table 4). Respondents aged more than or equal to 41 years had the highest religious acceptance compared with respondents aged between 18 and 25 years and 26 and 40 years (with mean scores of 5.28 and 5.26, respectively; Table 4). On the contrary, the respondents who possess a university-level education perceived the highest level of religious acceptance (with a mean score of 5.34), while the lowest level of religious acceptance was exhibited by those respondents with a secondary school level of education (with a mean score of 5.12; Table 4). Meanwhile, Hindus were found to have the highest mean score in terms of religious acceptance (with a mean score of 5.65) while the lowest religious acceptance level was indicated by Christians (with a mean score of 5.22; Table 4). These differences of opinion, however, do not differ significantly, as multivariate analysis could not detect any significant differences of the tested variables across age, education, and religion (Table 4).

**Behavioral Intention**

The overall mean scores for behavioral intention to adopt gene therapy was found to be high (with a mean score of 5.34; Table 4). Respondents older than 41 years accounted for the highest intention to adopt gene therapy (with a mean score of 5.48) compared with other age groups (Table 4). In addition, Muslims were found to have the highest intention to adopt gene therapy (with a mean score of 5.40) while the lowest intention was professed by Christians (with a mean score of 5.22; Table 4).
score of 5.20; Table 4). Despite the differences in the level of intention to adopt gene therapy, the multivariate analysis could not detect any significant differences across age and religion (Table 4). Meanwhile, respondents who possess university and pre-university level education were found to have a higher intention to adopt the technology (with a mean score of 5.44 and 5.30, respectively) compared with those with secondary school education (Table 4). MANOVA and post hoc tests confirmed that the intention to adopt gene therapy differed significantly across educational levels (Table 4).

### Discussion

The overall mean score for perceived benefits (with a mean score of 5.55) in this study are considered much higher than the perceived risks (with a mean score of 3.75; Table 4). This indicated that the Malaysian stakeholders in the Klang Valley viewed the benefits of gene therapy outweighing its risks; this, in turn, translates to a higher intention to adopt. This finding is comparable with those of previous studies which reported that an inverse relationship exists between the perceived benefits and the perceived risks (Amin et al., 2017, 2018; Frewer, 2017). Hashim et al. (2017) demonstrated that the intention to adopt was primarily influenced by the perceived benefits and by religious acceptance. Frewer (2017) also reported that risk and benefit perception are the key element with regard to successful new technology and product acceptance. Amin et al. (2017, 2018) previously also explained the intricate balancing relationship of the attitudinal factors, and their findings were supported by some earlier studies on public perception with regard to the use of biodiesel fuel and xenotransplantation.

However, despite having indicated that the technology was beneficial in terms of improving human health and being religiously accepted, the respondents in this study were found to be cautious in that they also acknowledged that gene therapy had moderate risks (with a mean score of 3.75; Table 4). This situation can be seen from past studies which have demonstrated that the public’s support toward gene therapy was often accompanied by concerns as to its possible risks. In Europe, gene therapy was seen to command major support from the public, but some aspects were likely to generate controversy, such as from a religious point of view (Allum et al., 2014). Hobbs et al. (2012) reported that people in the United Kingdom and Germany perceived biobanks as being beneficial to society, but risks such as personal privacy affected their willingness to take part in biobanking. Worries about possible risks could also be due to the technology being considered to be new and complex, which can be difficult to understand on the part of lay people.

Demographic factors are known to play a substantial role in influencing public perceptions of genetic modification.
The results of this study showed that the intention to adopt gene therapy and its predictors were affected by socio-demographic factors. One-way MANOVA has confirmed that the significant differences existed with regard to perceived benefit across age, and behavioral intention across education (Table 4). No significant differences were detected across religion (Table 4). Respondents aged 41 years and above tended to perceive gene therapy as being more beneficial than did the youngest group of respondents (18–25 years; Table 4). It is interesting to note that this finding is different from those of Ahram et al. (2013, 2014) who reported that the oldest individuals in Jordan had more negative perceptions toward biomedical research and biobanking than did younger respondents. A possible explanation for this is that in Jordan, there is a lack of awareness programs, government recognition, and financial support to promote public involvement in areas such as biomedical research (Ahram et al., 2014; Gaskell et al., 2013) and palliative care services (Khader, 2017). Meanwhile, in Malaysia, more effort has been made in helping Malaysians, especially the elderly, to become healthier through awareness campaigns to improve their overall health and well-being (Thestar, 2016).

The more educated respondents (pre-university and above) were found to be more willing to adopt gene therapy compared with those who have only secondary school education. This finding is in line with a study conducted by Delhove et al. (2020), in which respondents with better (self-reported) knowledge were shown to have more support for both gene therapy and gene editing technologies. Moreover, several studies have also reported that the higher the education of the respondent, the more beneficial they view the technology as being, and the more supportive they are toward the application (Amin et al., 2016; Hashim et al., 2017; Wang et al., 2017). This could be due to the fact that they were actively seeking information, thus shaping a more positive view toward the application. Morgan and Sternke (2010) mentioned that the educational level should be seen as a predictor of positive attitudes with regard to science and biomedical research. Furthermore, Evans and Kelley (2011) indicated that more highly educated respondents can be seen to be more supportive with regard to human embryonic stem cell research.

Meanwhile, there is no significant effect of religion on all variables (Table 4). Respondents from all religions were in agreement as to the benefits, risks, religious acceptance, and intention to adopt gene therapy. The presented result differs from that reported by Hashim et al. (2017), where all the respondents across religions perceive biobanks moderately with regard to benefits, risks, and religious acceptance. Meanwhile, all the religious groups exhibited a high degree of support toward biobanks, with the exception of Hindus, who showed a moderate level of support. On the contrary, the Buddhist respondents were found to be more supportive toward human embryonic stem cell research and differed significantly from the Muslims (Amin et al., 2016). Moreover, the Muslim respondents in Europe were also less optimistic toward technology compared with the Christian ones (Gaskell et al., 2010).

This is the first study of the influence of age, education, and religion on stakeholders’ intention to adopt gene therapy for the treatment of genetic diseases in Malaysia. Nevertheless, the findings of this study provide an important insight in terms of various socio-demographic characteristics despite limited coverage and highlighted the Malaysian view of gene therapy. However, it is important to address the limitations of the study such as the non-inclusion of other socio-demographic characteristics of the respondents. The presented results are valid in demonstrating Malaysian stakeholders’ intention to adopt gene therapy based on three socio-demographic characteristics. In future, there is a need for a study to focus on the intentions of the general public. Malaysia is a multi-ethnic country, so it is important to analyze the effect of other demographic variables such as stakeholder group, gender, and race on intention to adopt gene therapy. One of the challenges faced during the administration of the questionnaires was in getting feedback from patients. If the patients were not fit enough, family members who accompanied them were interviewed.

**Conclusion**

It can be concluded that gene therapy is positively viewed by the Malaysian stakeholders in this study, signaling a promising scenario for the use of the technology to treat various chronic disorders. The benefits, religious acceptance, and intention to adopt gene therapy were ranked as high, but there was some caution in that the stakeholders also acknowledge moderate risks. There is also an indication of the effect of background variables, noticeably age and education, which suggest the need for appropriate strategies such as more awareness programs for the younger and lower educational groups. This study serves as a useful baseline for scientists, government regulators, policy makers, and political leaders to understand Malaysians’ intention to adopt gene therapy technology and its predictors, with regard to its possible wider application in future. Although generalizing the findings is not recommended at this stage, the study may serve as a constructive benchmark in terms of Malaysian stakeholders’ intention to adopt gene therapy. Therefore, it is suggested that further research should be conducted in other states so that the results can be generalized. In addition, the part played by other demographic variables in shaping stakeholders’ intentions to adopt gene therapy could be considered.

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Ethical Approval and Considerations

This study has been approved by the Medical Research and Ethics Committee (MREC), Ministry of Health, Malaysia (MOH), reference number (E1160/1). Ethical considerations are important to protect the right of the participants, as well as to maintain the integrity of the study and the integrity of the researcher. Written informed consent was given before the respondents answered the questionnaires, and this was recorded by the enumerators. The participants involved in this study were assured of their anonymity and were informed that their views would be used for the purpose of the research only.

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