



**HUMAN EMBRYONIC RESEARCH: THE
MALAYSIAN REGULATORY FRAMEWORK,
HUMAN FERTILIZATION AND EMBRYOLOGY
ACT 1990 (UNITED KINGDOM) AND SHARIAH
PERSPECTIVE**

BY

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ABSTRACT

Today, human embryo has tremendously become one of the important subjects of research and experimentations. The research is regarded as very important in developing solutions for the treatment and prevention of infertility and other diseases or disorders in human. However, the field of embryo research has been followed by ethical, religious and legal controversies from the very beginning and these issues have been crucial in many decision-making. This study provides an analysis of the medical and legal aspects of research using human embryo under the UK and Malaysian regulatory framework. Shariah perspective on this topic is also comprehensively discussed as it is deemed to be indispensable especially in a country like Malaysia which gives special status to Islam as the official religion. This study principally seeks to answer FIVE (5) fundamental questions, namely: First: the extent to which UK legislations on embryo research or its precedent should be likely to be adopted by the Malaysian Legislature and courts, Second: the adequacy of the Malaysian regulation in regulating research activities involving human embryo, Third: the extent of desirability of regulating specific legislation on human embryo research among the local medical practitioners and scientists, Fourth: the extent to which the practice and research using human embryos would be accepted from the Islamic perspectives, and Fifth: the extent to which Islamic perspective should influence the Malaysian Legislature in the making of future legislation. The Malaysian regulatory framework concerning embryo research is not comprehensive and incomplete. There exist uncertainties, inadequacies, and inconsistencies in the existing guidelines relevant to research using human embryo, and the absence of adequate and effective controlling and monitoring system. These findings have led to the conclusion that, in order to effectively regulate research activities using human embryos, Malaysia need a model to follow. In relation to that, it is also the finding of this study that the UK experiences in determining the policy for, and in legislating embryo research has been proven to be of assistance in guiding Malaysia towards determining its own policy. The HFE Act 1990 in particular, has also provided useful guidelines for Malaysia in ascertaining the relevant provisions to be incorporated in Malaysian future legislation concerning embryo research. Study conducted on the general and specific comments and criticisms made to the Act have indeed been of help in pointing out certain important areas of the Act that need proper consideration and attention from Malaysia. With regard to the extent to which UK approach and its legislation should be likely to be adopted by the Malaysian Legislature, it has been proven by this study that the Islamic framework has proven to be of useful 'evaluating tool' in drawing up the limit of adoption. As such, it has become possible to determine the position of the HFE Act 1990 provisions from the Islamic point of view. Despite the popularly claim that the UK legislation is of a liberal one, it is apparent from this study that the provisions contained in the Act concerning embryo research are largely in concordance with the Islamic framework, except on few matters. In reliance to these conclusions, some recommendations considered as fundamental and pertinent to legislating embryo research in Malaysia have also been made. The recommendations addressed are meant not only to national policy-makers and scientific investigators, but also public and private research institutions, fertility centers, patients and wider communities.

الملخص

وقد أصبح اليوم موضوع الجنين البشري أحد المواضيع المهمة للبحث والتجريب. ويعتبر هذا البحث له أهمية بالغة في تطوير وتقديم حلول تتعلق بالعلاج والوقاية من العقم وأمراض أو اضطرابات أخرى لدى الإنسان. ومع ذلك في مجال البحوث للجنين قد اعتبته الخلافات الأخلاقية والدينية والقانونية من البداية حيث تعتبر هذه القضايا مهمة في الوصول إلى القرارات الكثيرة. وتقدم هذه الدراسة تحليلاً للجوانب الطبية والقانونية من الأبحاث التي تستخدم الأجنة البشرية في الإطار الإشرافي في المملكة المتحدة وماليزيا. وتتم أيضاً مناقشة هذا الموضوع من وجهة نظر الشريعة الإسلامية حيث لا يمكن الاستغناء عنها خصوصاً في بلد مثل ماليزيا الذي يعطي مكانة خاصة للإسلام والذي يعتبر الدين الرسمي للدولة. وتهدف هذه الدراسة مبدئياً للوصول إلى إجابة على خمسة (5) أسئلة أساسية، وهي أولاً: إلى أي مدى تشريعات المملكة المتحدة وقراراتها في مجال البحوث للجنين ينبغي أن يتم اعتمادها من قبل الهيئة التشريعية في ماليزيا ومحاكمها. وثانياً: مدى كفاية تشريعات ماليزيا في تنظيم الأنشطة البحثية التي تنطوي على الأجنة البشرية. وثالثاً: مستوى الرغبة في تنظيم تشريعات محددة بشأن أبحاث الأجنة البشرية بين الممارسين الطبيين المحليين والعلماء. والرابع: إلى أي مدى هذه الممارسة والأبحاث التي تستخدم الأجنة البشرية من شأنها أن تكون مقبولة من وجهة نظر الإسلام. والخامسة: إلى أي مدى يجب أن يؤثر المنظور الإسلامي على السلطة التشريعية الماليزية في وضع التشريعات في المستقبل. والجدير بالذكر أن الإطار التشريعي في ماليزيا بشأن بحوث الأجنة لم يكن شاملاً وكاملاً حيث توجد عناصر عدم اليقين وعدم كفاية وتناقضات في التوجيهات الحالية تتعلق بالأبحاث التي تستخدم الأجنة البشرية كما لا توجد مراقبة وإشرافية كافية وفعالة. وقد أدت هذه النتائج إلى استنتاج بأنه تحتاج ماليزيا إلى نموذج كمرجعية لأجل تنظيم أنشطة البحث باستخدام الأجنة البشرية بشكل فعال. وفيما يتعلق بذلك، وأيضاً من بين نتائج هذه الدراسة أن تجارب المملكة المتحدة في وضع السياسة والتشريعات على الأجنة البشرية قد ساهمت في توجيه ماليزيا نحو تحديد سياستها الخاصة. وبوجه خاص، قد قدم قانون إيس. إيف. إي. عام 1990 مبادئ توجيهية مفيدة لماليزيا في التحقق من المواد ذات الصلة لإدراجها في تشريعات ماليزيا في المستقبل فيما يتعلق ببحوث الأجنة. وتكون الدراسة التي أجريت على تعليقات عامة وخاصة وأيضاً الانتقادات الموجهة لهذا القانون قد تم بالفعل تساعد في توضيح بعض المجالات الهامة للقانون التي تحتاج إلى الاهتمام والنظر على النحو المناسب من ماليزيا. وفيما يتعلق بمدى نهج المملكة المتحدة وتشريعاتها ينبغي

أن يكون من المرجح للاعتماد عليه من قبل الهيئة التشريعية في ماليزيا، فقد توصل هذه الدراسة إلى أن الإطار الإسلامي يساهم كأداة تقييم في وضع الحد للتبني. ومن ثم فقد أصبح من الممكن لتحديد مكانة قانون إيس. إيف. إي. عام 1990 من المنظور الإسلامي. وعلى الرغم أنه شهيرا يدعى أن تشريع المملكة المتحدة ليبرالي، فمن الواضح من هذه الدراسة أن المواد الواردة في القانون المتعلقة ببحوث الأجنة هي إلى حد كبير تتوافق مع الإطار الإسلامي، إلا في بعض الأمور. وفي الاعتماد على هذه الاستنتاجات، تعتبر بعض التوصيات أساسا وأصلا في تشريع بحوث الأجنة في ماليزيا حيث قد تم تقديمها. والغرض من التوصيات المطروحة لا تقتصر لتوجيه واضعي السياسة الوطنية والمحققين العلميين فحسب، ولكن تعم أيضا لمؤسسات البحوث العامة والخاصة، ومراكز الخصوبة، والمرضى والمجتمعات.

APPROVAL PAGE

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PERSPECTIVE**

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DECLARATION

I hereby declare that this thesis is the result of my own investigations, except where otherwise stated. I also declare that it has not been previously or concurrently submitted as a whole for any other degrees at IIUM or other institutions.

Fadilah Binti Abd. Rahman

Signature:.....

Date: November 2011

This work is dedicated to:

*My Late Lovely Father, [Allahyarham Hj. Abd. Rahman Bin Mohd Noor (1939-
2008)],*

My Dear Mother, [Hajjah Memun Binti Hj Ibrahim],

My Beloved Husband, [Ahmad Suhaimi Bin Yahya],

And,

My Lovely Children, [Ahmad Afif, Ahmad Alif, Ahmad Arif]

May Allah bless them always...

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LIST OF ABBREVIATIONS

A.R.T	Assisted Reproductive Technology	JAKIM	Jabatan Kemajuan Islam Malaysia
AI	Artificial Insemination	LPPKN	Lembaga Penduduk dan Pembangunan Keluarga Negara.
CNR	Cell Nuclear Replacement	MLJ MMA	Malayan Law Journal Malaysian Medical Association
GIFT	Gamete intra-fallopian transfer	MMC	Malaysian Medical Council
HUKM	Hospital Universiti Kebangsaan Malaysia	MOH	Ministry of Health
HC	House of Commons	NPFDB	National Population and Family Development Board
HFE Act 1990	Human Fertilization and Embryology Act 1990	OGSM	Obstetrician and Gynecology Society Malaysia
HFE Authority	Human Fertilization and Embryology Authority	PCR	Polymerase Chain Reaction
HFE Act 1990	Human Fertilization and Embryology Act 1990	PGD	Pre-Implantation Genetic Diagnosis
HL	House of Lords	WHO	World Health Organization
ICSI	Intra-Cytoplasmic Injection	WMA	World Medical Association
IUI	Intra-uterine insemination		
FISH	Fluorescence in situ hybridization		
IMR	Institute of Medical Research		
IVF	In <i>Vitro</i> Fertilization		

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TRANSLITERATION TABLE

Table 1: Transliteration Table: Consonants

Arabic	Roman	Arabic	Roman
ب	b	ط	ṭ
ت	t	ظ	ẓ
ث	th	ع	'
ج	j	غ	gh
ح	ḥ	ف	f
خ	kh	ق	q
د	d	ك	k
ذ	dh	ل	l
ر	r	م	m
ز	z	ن	n
س	s	ه	h
ش	sh	و	w
ص	ṣ	ء	'
ض	ḍ	ي	y

Table 2: Transliteration Table: Vowels and Diphthongs

Arabic	Roman	Arabic	Roman
اَ	a	أَ، آ، إِي	an
أُ	u	أُو	un
إِ	i	إِي	in
أَ، آ، إِي،	ā	أَو	aw
أُو	ū	أَي	ay
إِي	ī	أُو	uww, ū (in final position)
		إِي	iyy, ī (in final position)

CHAPTER 1

INTRODUCTION

1.0 BACKGROUND OF THE STUDY

Today, human embryos have tremendously become one of the important subjects of research and experimentations. The researches are regarded as very important in developing solutions for the treatment and prevention of infertility and other diseases or disorders in human.¹ Many scientists urge for embryonic research particularly the embryonic stem cell research because of the potential benefits that it promises to human beings. Apart from their potential to treat or cure diseases, human embryonic stem cells also provide a model to study very early human development and some of the disorders that lead to birth defects and childhood cancers. Many of these disorders develop in early pregnancy and are impossible to study in humans. Also, human embryonic stem cells can be used to examine the genes that are turned “on” or “off” as stem cells generate more specialized cell types, permitting a unique understanding of the genetics of human development. The specialized cells derived from human embryonic stem cells can be used to study the effectiveness of potential new drugs to treat diseases. This provides a human cellular model and can reduce animal experimentation and drug development costs. Additionally, embryonic stem cells can be derived from human blastocysts with specific genetic abnormalities. These types of blastocysts are identified through genetic diagnosis during IVF treatment, to screen out genetically abnormal blastocysts, and are usually discarded. The stem cells from them can provide a unique resource to understand genetic diseases and to develop cures. Human embryonic stem cells could also be used to understand the origin or

¹ For a more detailed explanation on the potential contributions of embryo research, see Chapter 2.