EVALUATION OF ISLAMIC PERSPECTIVES REGARDING A MEDICAL CONDITION KNOWN AS DISORDERS OF SEX DEVELOPMENT (DSD)

By

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DECLARATION SHEET

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ABSTRACT

This study is conducted so as to evaluate Sunni Islamic perspectives concerning the medical issue known as Disorders of Sex Development (DSD). DSD is defined as a congenital condition in which development of chromosomal, gonadal or anatomical sex is atypical. It is a condition in which sex ambiguity occurs and can be detected within the scope of biological distraction. This issue is crucial since it severely impacts upon the identity of the patients and will lead to lower quality of life if the case is not managed in the best way.

In Islam, these issues are typically considered in the context of *khunūthah* (hermaphroditism), which remained unchanged in nature. However, current biomedical technology has increased our insight into this complex condition. Biomedical studies have appeared to provide a large amount of information on abnormal human biological development. However, the connection between these two fields has been given little attention. Dynamism of Islamic perspectives is required to resolve biomedical issues over gender ambiguity.

This research sets out, in order, to: i) conduct an in-depth research study from Islamic perspectives on cases related to sex ambiguity in terms of various types of *khunthā* and associated gender assignment by taking into account the type and the extent of the condition of DSD the patient is currently being faced with; ii) identify the Islamic bioethical underpinnings for DSD conditions affecting gender assignment, treatment and the decision-making process; and iii) determine the need for the involvement of Muslim scholars in a multidisciplinary team to manage patients with DSD.

As cultural context is inseparable from biomedical ethics, this study is conducted by acknowledging its regional context of South East Asian especially in exploring the latter objective in Malaysia, Indonesia and Singapore. The data is collected through analysis of written material, in-depth interviews and questionnaires. The findings show the connection between *khunūthah* and

DSD and the underlying concept of Islamic biomedical ethics opens a way to progressively move with current biotechnological findings on human biological development. It also becomes a tool in managing Muslim patients with DSD with regard to the gender assignment, the treatment and the decision-making process with the involvement of Muslim scholars in a multidisciplinary team.

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ABBREVIATIONS

AMLA	Administration of Muslim Law Act, Singapore
BAC	Bioethics Advisory Committee, Singapore
BIMAS	Guidance for Muslim Society (abbreviated from Malay: *Bimbingan Masyarakat*), Indonesia
CAH	Congenital Adrenal Hyperplasia
CAIS	Complete Androgen Insensitivity Syndrome
DSD	Disorders of Sex Development
DSD-TRN	Disorders of Sex Development-Translational Research Network
GOSH	Great Ormond Street Hospital for Children, United Kingdom
I-CAH	International Congenital Adrenal Hyperplasia Registry
I-DSD	International Disorders of Sex Development Registry
IKIM	Institute of Islamic Understanding Malaysia (abbreviated from Malay: *Institut Kefahaman Islam Malaysia*)
JAKIM	Department of Islamic Development Malaysia (abbreviated from Malay: *Jabatan Kemajuan Islam Malaysia*)
MDT	Multidisciplinary Team (in managing patients with DSD)
MUI	Council of Indonesian Scholars (abbreviated from Indonesian: *Majelis Ulama Indonesia*)
MUIS	Islamic Religious Council of Singapore (abbreviated from Malay: *Majlis Ugama Islam Singapura*)
MREC	Medical Review and Ethics Committee, Ministry of Health Malaysia
MRKH	Mayer-Rokitansky-Küster-Hauser syndrome
PAIS	Partial Androgen Insensitivity Syndrome

GLOSSARY

Medical Terms

ablation	removal or destruction of tissue by surgery, heat, hormones, or other drugs
aldosterone	a steroid hormone that is synthesized and released by the adrenal cortex and acts on the kidney to regulate salt (potassium and sodium) and water balance
androgen	one of a group of steroid hormones, including testosterone and dihydrotestosterone, that stimulate the development of male sex organs and male secondary sexual characteristics
androgen insensitivity syndrome	a disorder in which the body does not react to androgens because of structural abnormalities in androgen receptors
anti müllerian duct hormone	hormone that suppresses the growth of the Müllerian duct
autosome	any chromosome that is not a sex chromosome
clitoroplasty	surgical reduction of the clitoris
chordee	abnormal curvature or angulation of the penis
congenital adrenal hyperplasia	a family of autosomal recessive genetic disorders
cortisol	a steroid hormone
gender dysphoria	a condition in which an individual belongs to one gender on the basis of physical appearance and genetics but identifies psychologically with the other gender
genotype	genetic constitution of an individual or group
gonad	a male or female reproductive organ that produces the gametes; ovary and testis
gonadectomy	removal of an ovary or a testis
gonadoblastoma	a rare tumour that is made up of more than one type of cell found in the gonads (testicles and ovaries)

hypogonadotrophic hypogonadism	clinical syndrome that results from gonadal failure and can cause issue of fertility
hypospadias	a congenital abnormality in which the opening of the urethra is on the underside of the penis
karyotype	characterization of the chromosomal complement of an individual or a species including number, form and size of the chromosomes
klinefelter syndrome	a genetic disorder in which there are three sex chromosomes, XXY, rather than the normal XX or XY
minor patient	children and infant patients
mosaicism	an individual or cell cultures having two or more cell lines that are karyotypically or genotypically distinct but are derived from a single zygote
neonate	an infant at any time during the first 28 days of life
oestradiol	major female sex hormone produced by the ovary
oestrogen	one of a group of steroid hormones that control female sexual development, promoting the growth and function of the female sex organs and female secondary sexual characteristics
phenotype	observable characteristics of an individual
phimosis	narrowing of the opening of the foreskin
pituitary gland	master endocrine gland
seminal vesicle	either of a pair of male accessory sex glands that open into the vas deferens before it joins the urethra
testosterone	principal male sex hormone
thelarche	breast development
turner syndrome	a genetic defect in women in which there is only one x chromosome instead of the usual two
vaginoplasty	surgical reconstruction of the vagina

virilisation	most extreme result of excessive androgen production

Arabic Words

ʾuṣūliyyūn	experts in the discipline of principles of Islamic jurisprudence
ʿadl	social justice
ʿalamāt	signs
adillah al-aḥkām	proof of injunctions
aḥkām	rulings or
aḥkām al-mufaṣṣal	detailed injunctions
aḥkām al-mujmal	comprehensive injunctions
aḥkām al-mujmal wa al-mufaṣṣal	comprehensive and detailed injunctions
ahl al-khibrah	experts
ahliyyah	competence
ahliyyah al-adāʾ al-qāṣirah	deficient executive capacity
ahliyyah al-wujūb al-kāmilah	complete receptive capacity
ahliyyah al-wujūb al-nāqiṣah	imperfect receptive capacity
al-aḥkām al-fiqhiyyah	legal injunctions
al-akhlāq	ethics
al-athar	a narration by a Companion or a Follower recorded based on his verbal or action
al-ʾiʿtiqādiyyāt	beliefs
al-maʿtūh	a person with learning and cognitive disability
al-maḥkūm fīh	the subject-matter of ruling
al-mushtarak	homonym

al-qawāʿid al-lughawiyyah	linguistic methodologies
al-safīh	unintelligent person
al-sharīʿah al-islāmiyyah	Islamic law
al-tābiʿīn	the followers
aṣl	original
	one of the elements of *qiyās:* an original case on which its ruling is given in the text and analogy seeks to extend it to a new case.
ʿām	general
bulūgh	puberty
ḍarūrah	Dire need
ḍarūriyyāt	necessities
ḍiyā	waste
farʿ	one of the elements in *qiyās*; a new case that requires determination of Islamic rulings
fiqh	understanding, comprehension or science of understanding Islamic law
fuqahāʾ	Muslim jurists
ḥaḍānah	custody
ḥājiyyāt	complimentary
ḥalāl	praiseworthy
ḥarām	blameworthy; forbidden
ḥaqq	rights
hibah	gift
ḥujjah	proof
ḥukm	ruling/law
ḥukm al-mabāl	ruling attributed to the urinary tract
ʿibādah	worship

ʾijmāʿ	consensus of Muslim jurists
ʿillah	ratio legis
ijtihād	effort of a jurist makes in order to deduce the law, which is not self-evident, from its sources
ʿilm	knowledge
isnād	chain of transmission
istiḥsān	juridical preference
istiṣḥāb	presumption, continuity
istiṣlah	public interest
khāṣ	specific
khilāfah	trusteeship
khunthā	hermaphrodite
khunthā mushkil	intractable *khunthā*
khunthā wāḍiḥ	discernible *khunthā*
mafhūm mukhālafah	divergent meaning
mafsadah	harm
makrūh	discouraged
maḥkum alayh	the person whose act invokes a ruling or a ruling requires him to act in a prescribed manner
mandūb	recommended
maṣlaḥah	consideration of public interests by preserving the faith, mind, life, progeny and wealth either through protecting them or avoiding harms
mubāḥ	permissible
mujtahid/mujtahidūn	a person or a group of people who exercises independent reasoning (*ijtihād*) in the interpretation of Islamic law
munāsib	appropriate
munḍabiṭ	constant
mutaʿaddiy	transferable

qānūn	law
qaṭʿi al-thubūt	definitive state
qiyās	analogical reasoning
rushd	prudence
ṣaḥābah	Companions of the Prophet Muḥammad
ṣalāh	prayer
taḥsiniyyāt	embellishment
takhrīj al-ḥadīth	a method of validating the chain of transmitters and grading the authenticity level
tawātur	verbal perpetuation
tawḥīd	unity
uṣūl al-fiqh	principles of Islamic jurisprudence
wājib	obligatory
ẓannī al-thubūt	speculative proof
zimmah	the covenant of God
ẓuhr	visible

TRANSLITERATION

All Arabic words are transliterated based on original spelling (not on pronunciation) except for Anglicised places name such as Beirut and Mecca. It is based on Brill's simple Arabic transliteration system with some adaptations. The name of ʿAbdullah also is not transliterated in the specified way, i.e. ʿAbd Allah, to avoid any confusion with the single word of Allah. Other than that, transliteration is used.

Arabic	Transliteration	Example (Arabic)	Example (Transliteration)
Consonants			
ب	b	باب	*bāb*
ت	t	تاريخ	*tārīkh*
ث	th	ثروة	*tharwah*
ج	j	جاثية	*jāthiyah*
ح	ḥ	حاجة	*ḥājah*
خ	kh	خنثى	*khunthā*
د	d	دم	*dam*
ذ	z	ذريعة	*zarīʿah*
ر	r	ضروري	*ḍarūriy*
ز	z	زار	*zār*
س	s	سلام	*salām*
ش	sh	شخص	*shakhṣ*
ص	ṣ	مصلحة	*maṣlaḥah*
ض	ḍ	ضروري	*ḍarūriy*
ط	ṭ	مناط	*manāṭ*
ظ	ẓ	ظروف	*ẓurūf*

ع	ʿ	شريعة	*sharīʿah*
غ	gh	غني	*ghaniy*
ف	f	ظروف	*ẓurūf*
ق	q	واقع	*wāqiʿ*
ك	k	مكلف	*mukallaf*
ل	l	قول	*qawl*
م	m	مشكل	*mushkil*
ن	n	مناط	*manāṭ*
هـ	h	هيئة	*hayʾah*
و	w	واضح	*wāḍiḥ*
ي	y	يوم	*yawm*
ء	ʾ	مؤمن	*muʾmin*
ة	h	ثروة	*tharwah*
Short Vowels			
◌َ	a	رَمز	*ramz*
◌ِ	i	وِفق	*wifq*
◌ُ	u	جُزء	*juzʾ*
Long Vowels			
◌َا	ā	وَاضح	*wāḍiḥ*
◌ِي	ī	شرِيعة	*sharīʿah*
◌ُو	ū	ظرُوف	*ẓurūf*
Diphthongs			
أَوْ	aw	قَوْل	*qawl*
أَيْ	ay	هَيْئة	*hayʾah*

Double			
ّ	double letter	ضروريّة	*ḍarūriyyah*

All transliterated words including name of the books are italicised, except for:

1. The names of people.
2. The most common used words such as the Qurʾān, Ḥadīth, Sunnah and sharīʿah.

Qurʾanic References

When reference is made to the Qurʾanic text, the reference will indicate the name of *Sūrah* (Chapter), number of *Sūrah* and number of verse without the publication as the details of the verse are consistent in all publications. While the translations vary from one to another, the researcher refers to the translation based on ʿAbdullah Yūsuf ʿAlī, *The Holy Qur´an Text, Translation and Commentary*, New Revised edn (Brentwood: Amana Corporation, 1989). The variation is due to several factors including multiple definitions of an Arabic word depending on the context. Self-translation will be mentioned if it is required.

1. INTRODUCTION

1.1. Introduction

The relationship between science and religion is complex. Based on various scholarly analyses, divine revelation is sometimes being integrated with human scientific advancement or is perceived as complementing each other or even conflicting between one against the other. There are numerous efforts in assessing the role of religion in the development of modern science. Islam is not excluded from this discussion. History has recorded since ancient civilisations, like in Mesopotamian, Egyptian and Greek civilisations, that Muslim scholars have made respectable contributions in various fields of natural science such as in astronomy, mathematics, astrology and medicine. Those fields have been closely linked with the content of the Qurʾān, the main source of Islamic teachings, as well as the Ḥadīth. Today, as Islam highlights the importance of health in the lives of individuals, the debate encompasses both the legal and ethical juridical approach of Islamic rulings within biomedical issues.

Islam is governed by sharīʿah, a divine set of principles and guidance, which is usually known as Islamic law. The dimension of sharīʿah implies two aspects, firstly as a legal ruling and secondly as a moral code. Both of them are very much related to the discussion on biomedical issues.[1] Hence, sharīʿah will be studied thoroughly as it is the primary tool for Muslims' engagement with modernity.[2] It is best to state that the term 'Islamic perspectives' within this research will be confined to the theological base of Islamic teachings. The word 'perspectives' may imply the state of 'understanding how important things are in relation to others'.[3] In order to achieve this understanding, the discussion from theological viewpoints will serve as the most fundamental element. It is hoped this Islamic theological understanding will provide a structural overview in discussing a particular medical context that can be adapted later in broader context

[1] Aasim I. Padela, 'Country Report: Islamic Ethics: A Premier', *Bioethics*, 21 (2007), 169-178, p. 171.

[2] Aasim I. Padela, 'Islamic Bioethics: Between Sacred Law, Lived Experience and State Authority', *Theoretical Medicine and Bioethics: Philosophy Medical Research and Practice*, 34 (2013), 65 – 80, p. 67.

[3] *Oxford Paperback Dictionary and Thesaurus*, ed. by Maurice Waite and Sara Hawker, 3rd edn (New York: Oxford University Press, 2009), p. 682.

within various backgrounds of cultures, policies, practices and values among Muslim societies.

The Qurʾān and Ḥadīth are the primary sources of sharīʿah. These divine revelations provide appropriate essential references related to numerous issues including that of human creation and gender. Besides, *ʾijmāʿ* (consensus of Muslim scholars), is regarded unanimously by the Companions, the followers (*al-tābiʿin*) and Muslim jurists as the proof (*ḥujjah*) in Islamic Law.[4] The delineation of *ʾijmāʿ* as consensus among jurists (*fuqahāʾ*) after the demise of the Prophet regarding a specific issue at a specific time is also reflected in the collective decision (*fatwā*) made by contemporary scholars on current issues.[5] Hence, these three sources, apart from other forms of *ijtihād* will become the basis of discussion from the Islamic point of view on a particular medical condition in this research.

Being a researcher at a federal governmental department, the researcher was referred to by some doctors for a few complicated cases on gender ambiguity to be analysed from the Islamic perspectives. This triggered the researcher's inquisitive mode to explore more on this subject, particularly from the scope of the principles of Islamic jurisprudence. Thus, this study is conducted to evaluate Islamic perspectives concerning the medical issue known as Disorders of Sex Development (DSD). DSD is defined as a congenital condition in which development of chromosomal, gonadal or anatomical sex is atypical.[6] It is a condition in which sex ambiguity occurs and can be detected within the scope of biological distraction. DSD can occur with or without ambiguous genitalia, disjunction of internal and external sex anatomy, incomplete development sex anatomy, sex chromosome anomalies, disorder in gonadal development (the development of ovaries and testes) or a mixture of two or more of these factors.[7] Modern biomedical technology has increased our insights into this complex condition. This issue is crucial since it severely impacts upon the identity of

[4] Badr al-Din Muḥammad ibn Bahādur Al-Zarkashī, *al-Baḥr al-Muḥīṭ fī ʾUṣūl al-Fiqh (the Vast Explanation of the Principles of Islamic Jurisprudence)*, ed. by ʿAmmar Sulaymān al-Ashqar, vol. 4 (Al-Ghardaqah: Dār al-Ṣafwah, 1988), p. 441.

[5] Badr al-Din Muḥammad ibn Bahādur Al-Zarkashī, p. 436.

[6] I. A. Hughes, 'Disorder of Sex Development: A New Definition and Classification', *Best Practice & Research Clinical Endocrinology & Metabolism,* 22(1) (2008), 119 – 134, 120.

[7] Consortium on the Management of Disorders of Sex Development, *Clinical Guidelines for the Management of Disorders of Sex Development in Childhood* (North America: Accord Alliance, 2006), p. 2 <http://www.dsdguidelines.org/htdocs/clinical/index.html> [accessed 12 december 2014].

the patients and will lead to a lower quality of life if the case is not managed in the best way. Apart from gender identity, some patients with DSD may experience sexual attraction to others of the same gender as they were raised as; and hence be considered as “homosexuals” or they may have been behaving as the opposite gender from which they were initially raised to be.

1.2. Importance of the Study

A study by Gönül Öçal in 2011 indicates that one in every 4500 births has abnormality in his/her genital appearance, inclusive of those cases residing in Muslim countries; the nature of the abnormality being dependent on the type of the DSD affecting the individuals concerned.[8] A study in Egypt between 1966 and 2009 shows that out of 28,735 patients registered at the Medical Genetics Centre, 908 patients were confirmed clinically as DSD cases.[9] While in Turkey, between 1983 and 2002, there were 70 recorded cases of Congenital Adrenal Hyperplasia (CAH) problems, with CAH being one of DSD conditions.[10] Over a five year period of experience, Sudan’s Paediatric Endocrinology Clinic also carried out a study on DSD among Sudanese children. It is reported that 156 cases were observed in this research.[11]

In Malaysia, the data on DSD has not been properly recorded and even data on CAH, which is the most prevalent type of DSD in Malaysia, is limited.[12] However, in 1994, a study done using the birth rate at the Maternity Hospital and the patients referred to the Paediatric Endocrine Unit of Kuala Lumpur Hospital shows that there are CAH cases at 1: 3,000.[13] While in Indonesia, 347 patients of gender ambiguity were evaluated clinically by the Sexual Adjustment Team at Central Java Hospital between

[8] Gönül Öçal, 'Current Concept in Disorders of Sexual Development', *Journal of Clinical Research in Pediatric*, 3 (2011), 105 p. 105.

[9] Rabah M. Shawky and Sahar M. Nour El-Din, 'Profile of Disorders of Sexual Differentiation in the Northeast Region of Cairo, Egypt', *Egyptian Journal of Medical Human Genetics*, 13 (2012), 197-205, p. 197

[10] Hüsoyin Özbey and others, 'Gender Assignment in Female Congenital Adrenal Hyperplasia: A Difficult Experience', *BJU International*, 94 (2004), 388-391, p. 388.

[11] M. Abdullah and others, 'Disorder of Sex Development among Sudanese Children: 5-Year Experienced of A Pediatric Endocrinology Clinic', *Journal of Pediatric Endocrinology & Metabolism*, 25 (2012), 1065-1072, p. 1065.

[12] Wan Noor Hayati Wan Alias, ‘Malaysia Tiada Data Lengkap Khunsa (Malaysia Does Not Have a Complete Database on Hermaphrodite)’, *Berita Harian*, Laporan Eksklusif BH, 8 March 2015; Subashini Chellapah Thambiah and others, ‘Clinical Presentation of Congenital Adrenal Hyperplasia in Selected Multiethnic Population’, *Malaysian Journal of Medicine and Health Science*, 11 (1) (January 2015), 77-83, p. 78.

[13] Subashini Chellapah Thambiah and others, p. 82.

1989 and 2010.[14] In general, these research indicate that the number of people with this condition in Islamic countries is not low. The challenges facing those with this malaise involve gender assignment or reassignment, a decision making process, the time required and method of treatment itself.

These phenomena raise numerous questions among many Muslim physicians, patients, parents/guardians as well as the community in general on how to address this issue in the light of Islamic perspectives. In Islamic tradition, there is a condition known as *khunthā* (hermaphrodite) which is identified based on the ambiguity of one's genitalia. Initially, the importance of dealing with this circumstance is because the determination of gender influences most parts of a Muslim's life including religious obligations and his/her social life. Furthermore, by looking into the discussion of *khunthā* in Islam, medico-legal and ethical issues may be mitigated from Islamic perspectives hence giving more options for the physicians to deal with Muslim patients with DSD. At the societal level, this study is essential in order to provide better and accurate information on *khunthā* and DSD, thus unlocking ways for social and moral support to patients and their families.

1.3. Issues in Islam and Disorders of Sex Development

Presently, biomedical research does not merely look into the physical genitalia when it comes to gender issues, but also includes disjunction of internal organs as well as chromosomal factors which covers broader aspects than previously have been discussed by the classical Muslim scholars. Hence, the first question here is, is it possible to define DSD as *khunthā*? And, to what extent can the various types of DSD be incorporated into the two types of *khunthā,* i.e. *khunthā wāḍiḥ* (discernible hermaphrodite) and *khunthā mushkil* (intractable hermaphrodite)?

Secondly, as soon as the patient is identified with having DSD, the diagnosis aspect becomes the foremost action prior to following up with the necessary relevant clinical procedures. The results will lead to gender assignment, then treatment will take place.

[14] Annastasia Ediati, 'Disorders of Sex Development in Indonesia: The Course of Psychological Development in Late Identified Patients' (Doctor of Philosophy, Diponegoro University, Semarang, Indonesia, 2014), p. 19.

This raises another debate on how Islam views gender assignment for an infant or a child, and gender reassignment for an adult. It is because Muslim jurists also had outlined specific rules in determining gender for *khunthā.*

Thirdly is the query of the authority that a particular person has in making such decision. Conflict may arise between the doctors, adult patients, parents or guardians of a child or even among religious experts who are expected to advise on the Islamic point of view, because all of them have their own cultural, practical and religious beliefs at the back of their minds. In the minor (infant) patients' circumstance, the concern is related to the child rights and to what extent Islam is compatible with current civil law and medical practice on the procedure to be followed for DSD.

The greatest challenge for the physicians is to provide adequate treatment for the patients. A deep analytical review is also required over the question of hormonal and surgical treatments. Those treatments may sometimes lead to ineffective results due to unpredictable effects and the varying conditions of the patients. In order to minimise the risks, physicians are still trying to identify the best technique and the appropriate time to provide the treatment. These decisions and procedures are also related to ethical issues that can be resolved through Islamic underpinnings.

Therefore, this research focuses on the debate within the parameters of Islamic perspectives since Islam has its own rules regarding the so called *khunthā* circumstances. Referring to the basic sources of Islamic jurisprudence, classical Muslim scholars have discussed this issue in terms of its definition and gender assignment. They have also outlined how religious obligations, for instance, on how prayers and inheritance should be conducted whilst the exact gender of the patient cannot be determined. However, the researcher believes the discussions to be engaged in should be expanded by considering the actual situation being faced by an individual at that specific juncture of time.

1.4. Objectives and Aims

The ultimate aim of this study is to provide Muslim communities especially Muslim scholars and medical practitioners with the necessary guidelines to handle DSD

according to Islamic practices and principles. Hence, the objectives of this research are:

a. to evaluate the relationship between *khunūthah* (hermaphroditism) and associated gender assignment with the various types and complications of DSD the patient is faced with;
b. to identify Islamic bioethical underpinnings for DSD conditions that affect gender assignment, the decision making process and treatment; and
c. to determine the need for the involvement of Muslim scholars in multidisciplinary teams to manage patients with DSD.

1.5. Scope of the Research

The focus of this research is on the theological framework of sharīʿah and its applied concepts on the ensuing medical issues. This research is limited to the Sunni methodology as it is legally upheld by the laws in Malaysia and is widely practiced in Malaysia, Singapore and Indonesia, the three regional countries that will be studied. The Shāfiʿī school of thought within the Sunni perspectives will be given due consideration, the other three schools of thought, which are Mālikī, Ḥanāfī and Ḥanbalī, will be referred to if and when deemed necessary. The application of Islamic jurisprudence as has been applied in Singapore and Indonesia as Muslim minority and Muslim majority countries respectively will be observed. Issues of DSD in these countries will be highlighted in a broad-spectrum while discussing them from the Islamic perspectives. They will not be examined in detail to ensure this study is contained within its main scope.

Meanwhile, this research on DSD conditions will observe the flexibility of Islamic jurisprudence within the current medical issues surrounding the occurrence of DSD. Therefore, a clear understanding of DSD is essential. However, this condition may sometimes show overlapping characteristics, although in minor ways only. For example, cases with psychological disorders having no clear evidence of any biological disturbance do occur, but the discussion of the latter would involve an altogether different scope of study. This research will not put any emphasis on that area. In order to ensure the clarity of this critical periphery, a brief distinction between these two phenomena will be explained in a later subtopic.

Apart from that, since the main focus is on Islamic laws, the thesis will reflect the needs of Muslim patients and their families. Without ignoring the fact that Malaysia, Singapore and Indonesia consist of multiple races and multi-religious communities; time constraints should be given due consideration too. Therefore, this study will not examine the actual experiences of Muslim patients. It will focus purely on the theological underpinnings of Islamic law in relation to DSD. Other related aspects such as psychological impacts will need further research. The case studies that are included in this research are used to illustrate the complexity and its impact on the Islamic approach to deal with the complexity of such matters.

This study is a preliminary groundwork demonstrating how the theoretical Islamic principles in a few specific cases can be extended to be applied more generally in the many varieties of DSD that appear. Although the points of view of experts were taken into consideration throughout this research, more data needs to be collected to fully understand the lived experiences of Muslim patients and families, physicians' understanding and practice as well as social awareness of Islamic principles pertaining to DSD.

1.6. Methodology

The study of religion is normally associated with a lack of a distinct methodological approach and borrowed methods and rationales of study from various disciplines within humanities and social sciences.[15] Research design is governed by research philosophies, including ontological, epistemological, axiological and methodological beliefs which are then can be interpreted with various frameworks of positivism, post-modernism, empiricism, pragmatism and others. However, based on previous research conducted elsewhere and up to this date, the researcher found that these philosophies and the interpretive frameworks are incongruent with the domain of this research, i.e., Islamic studies. While conducting related research, the researcher has often employed the principles of Islamic jurisprudence in looking for solutions for any matters which may arise. This was not an issue for such research because it was

[15] Wade Clarke Roof, 'Research Design', *The Routledge Handbookof Research Methods in the Study of Religion*, ed. by Micheal Stausberg and Steven Engler (London: Routledge, 2011), 68 – 70, p. 68.

intended to seek Islamic rulings. The present research is not particularly designed to deduce such rulings. Rather, it aims to evaluate the relationship between Islamic perspectives and medical condition in a larger context.

The researcher employed a conventional research design which has been adapted to an Islamic worldview. The main elements of conventional design within what is known as a 'research onion' were preserved. The differences were on choices of alternatives in looking for the appropriate philosophical basis and its interpretive framework, data collection and data analysis. This is based on the proposal made by Waseem Gul as presented in Figure 1. Research design is 'the overall plan or strategy for achieving the aim(s) of a particular inquiry.'[16] It begins with philosophical assumption or epistemology, which is important in the study of religion.[17] It underlies the belief or idea that inform our research, including, for example, on what knowledge available; what constructs the body of knowledge; and what the sources of knowledge.[18] Instead of referring to conventional philosophy, the researcher refers to Islamic philosophy. This transformation is comparable in other field of studies such as in management studies. According to Azhar Kazmi, Islamic perspectives in management studies are an emerging field of enquiry in academia.[19] He proposed broad contours of research agenda, which is a framework to guide research activities in the management studies from Islamic perspectives. Nonetheless, his proposal is general in its sense. Later, Waseem Gul echoes Kazmi and provides more detail explanations on how this philosophy can direct the goals of research and its outcomes.[20] Gul named this philosophy as *Tawḥīdic* paradigm, or the paradigm of the Oneness of God. This philosophy is rooted in the very essence of the belief on One True God, Allah the Creator and the All-Knowing, and the knowledge about Allah was sent down to His Messengers through the Qurʾān and Ḥadīth. This forms the world view, which is

[16] Wade Clarke Roof, p. 69.

[17] Jeppe Sinding Jensen, 'Epistemology', *The Routledge Handbookof Research Methods in the Study of Religion*, ed. by Micheal Stausberg and Steven Engler (London: Routledge, 2011), 40 – 53, p. 40.

[18] Jensen, p. 41; John W. Creswell and Cheryl N. Poth, *Qualitative Inquiry and Research Design – Choosing Among Five Approaches* (California: SAGE Publications Ltd., 2018), p. 49.

[19] Azhar Kazmi, 'Probable Differences among the Paradigms Governing Conventional and Islamic Approaches to Management', *International Journal of Management Concept and Philosophy*, 1(4) (2005), 263 – 289, p. 269.

[20] Waseem Gul, 'Strategy: Can a Research Methodology be Proposed from Islamic Sources of Knowledge?' *International Business Research,* 12 (7) (2009), 83 – 95, p. 89.

reflected in their individual and collective live. These operate in coherence and synchronization to achieve the higher objectives of sharīʿah (*maqāṣid al-sharīʿah*).

The philosophical assumption in qualitative study is conveyed through interpretive framework in term of its central points, and how it informs the research problem, research question, data collection and analysis, and interpretation.[21] For example, in a conventional structure, research based on epistemological belief may use postpositivism or social constructivism as the interpretive framework. In this research, following the Islamic philosophy, the working interpretive framework is Islamic law. By considering this framework, the research problem was identified as presented in subtopic 1.3 and subsequently developed along with the research objectives.

In achieving the objective of this research, a qualitative method has been used by employing Case Study Design as the approach of inquiry. John W. Creswell and Cheryl N. Poth mentions there are three variations of case study, namely, instrumental case study, multiple or collective case study and intrinsic case study.[22] Within this research, an instrumental case study is employed by examining Disorders of Sex Development (DSD) when evaluating and analysing Islamic perspectives. Creswell and Poth argue that single case is most promising and useful compared to multi-cases.[23] Detailed descriptions of the case are presented through data collection and analysis. Robert K. Yin recommends six types of information to collect, which are documents, interviews, archival records, direct observation, participant observation and physical artifacts. The first two sources were used in this research.[24]

The researcher's personal experience was utilized in conducting this research. The researcher played her role as an insider researcher or *emic*, who Andrew H. van De Ven referred to, as 'a participant immersed in the actions and experiences within the system being studied'.[25] The researcher was a research officer at the Research Division, Department of Islamic Development Malaysia (abbreviated in Malay as

[21] John W. Creswell and Cheryl N. Poth, p. 73.
[22] John W. Creswell and Cheryl N. Poth, p. 157.
[23] John W. Creswell and Cheryl N. Poth, p. 159.
[24] Robert K. Yin, *Case Study Research and Application – Design and Methods* (London: SAGE Publications Ltd., 2018), p. 172.
[25] Andrew H. van De Ven, *Engaged Scholarship* (Oxford: Oxford University Press, 2007), p. 270.

JAKIM – *Jabatan Kemajuan Islam Malaysia*). The experience of conducting research pertaining to the issue of sex ambiguity from Islamic perspectives and dealing with the real-life cases offered a better perspective for this particular study. The researcher also engaged in a Shariah Expert Panel, Department of Islamic Development Malaysia (JAKIM).[26] This is a platform where all research conducted should be presented for further discussion and decision making by the members of the panel. An 'insider status', in this situation, can help to build trust or rapport based on shared experiences and values and make it easier to discuss any sensitive issue.[27]

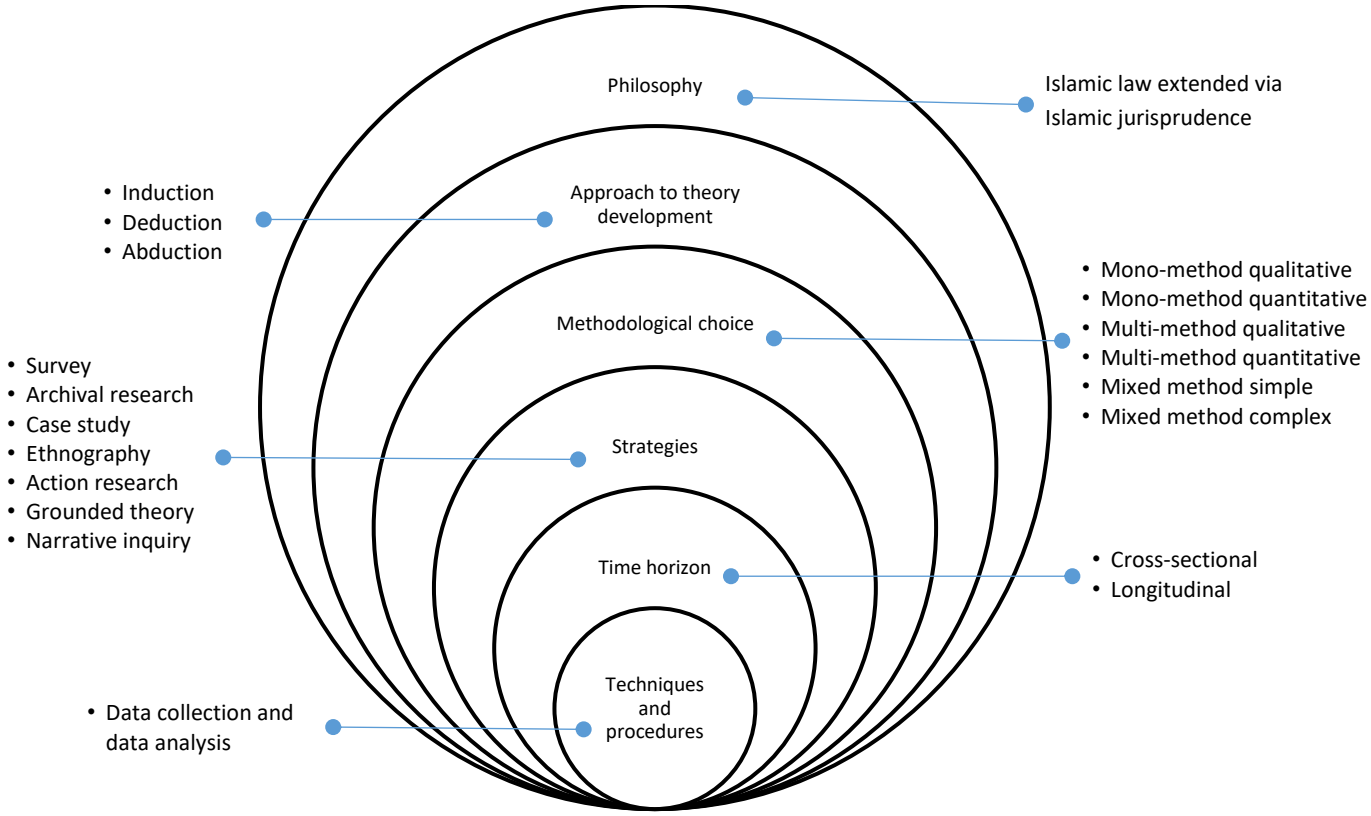

Figure 1: The Research Onion from Islamic Perspectives

1.6.1. Data Collection

The data was collected in seeking the information required to fulfil the objectives of this study, from interview and documents as presented below.

[26] Department of Islamic Development Malaysia is a federal governmental department, which is responsible for managing administration of Islamic affairs. More details of the Shariah Expert Panel and the Department of Islamic Development Malaysia can be found in Chapter 7.

[27] Janet Salmons, 'Designing and Conducting Research with Online Interviews', *Cases in Online Interview Research*, ed. by Janet Salmon (United States: SAGE Publication, 2012), p. 16.

1.6.1.1. Interview

The first method of data collection used in this research was semi-structured interviews in which primary data were obtained. Interview are commonly used in conducting qualitative research when some or occasionally all of the data are collected through this method.[28] Roof acknowledges that semi-structured interviews are appropriate for the research under discussion in religious studies, since they combine major questions asked of everyone with open-ended, exploratory questions.[29] This allowed the researcher to query in greater depth to obtain adequate information, particularly from Islamic scholars in Malaysia, Singapore and Indonesia, and also from medical practitioners in Malaysia. The advantages of selecting this method were that it allowed qualitative data to be collected directly, it was flexible and eased transformation of data.

Purposeful sampling was employed to identify respondents for the interviews. They were selected from amongst experts with Islamic studies and medical backgrounds. They were identified by their contributions to scholarship; either from published documents or unpublished work, or their involvement with and contributions in multidisciplinary team managing patients with DSD. Having been involved in the Shariah Expert Panel, Department of Islamic Development Malaysia (JAKIM) for eight years enabled the researcher to acquire substantial networking with both the medical team and religious experts.

While it was difficult to identify Islamic scholars, who have relevant information or experience in handling cases related to Islam and DSD, six Islamic scholars in Malaysia were selected based on their expertise and knowledge, especially with regard to Islamic biomedical ethics and gender discourse. One of them was female, who was also among four respondents who were members of the Shariah Expert Panel, Department of Islamic Development Malaysia (JAKIM). Among those members are two muftis, appointed by the Rulers of two different states in Malaysia, i.e. Federal Territories and Pahang. Islamic scholars from Singapore and Indonesia were selected by their authoritative positions in the respective countries. The choice was made to

[28] Sharan B. Merriam, p. 87.
[29] Wade Clarke Roof, p. 74.

analyse the involvement of Islamic authorities in managing patients with DSD in order to address the third objective of this study. The respondents were Mufti of Singapore (at the time of interview – currently, new Mufti was appointed), members of *Majelis Ulama Indonesia* (Council of Indonesian Scholars) and an officer at the Ministry of Religious Affairs, Indonesia, all of whom were males.

Additional participants were six physicians from Malaysia that have specialised in issues related to DSD. Unlike the Islamic scholars, all except one were female. They included paediatric and adolescent gynaecologists, an endocrinologist, a geneticist, a psychiatrist and a director at the Ministry of Health, Malaysia. All of them have extensive clinical experience in various intersex syndromes. Each is a prominent researcher in their areas of specialization. The name of the respondents, their positions and details of the interviews are presented in Table 1. Two requested anonymity and agreed to disclose their organization they had served previously as to indicate credibility of the information. Although Katjia Guenther argues that concealing the name of an organization often does little to achieve internal confidentiality, this does not have adverse effect on the organization.[30]

The researcher utilised multiple forms of interview methodology to ensure that the information could still be gathered, despite the geographical distance and time differences between the United Kingdom and the South East Asian region, i.e. Malaysia, Singapore and Indonesia. The most common form, as basically understood from the word 'interview' is face to face conversation. The second forms of interview are through electronic devices, namely, telephone conversation and Computer-Mediated Communication (CMC). Telephone is an alternative to face-to-face conversation, where respondents have been described to be 'relaxed on the telephone and willing to talk freely and to disclose intimate information'.[31] On the other hand, CMC form of interview for qualitative research enables the data to be collected through synchronous communication like a video call or asynchronous at any time like an email.[32]

[30] Katjia Guenther, 'The Politics of Names: Rethinking the Methodological and Ethical Significance of Naming People, Organizations and Places', *Qualitative Research*, 9(4) (2009), 411 – 421, p. 418.

[31] Gina Novick, 'Is There a Bias against Telephone Interview in Qualitative Research', *Research in Nursing and Health* 31 (2008), 391 – 398, p. 393.

[32] Janet Salmons, pp. 3 – 4.

The video call is an extended form of the phone call technique where the non-verbal expression can be observed too. Skype application was used in this study. While other forms of interview seemed to be detrimental to conduct verbal communication due to certain factors, CMC facilitates the use of email within qualitative research strategies.[33] This method is useful when issues on time and space, sensitive information, convenience and social presence are taken into consideration.[34] In this research, this method was used in order to allow the respondents to reply to the questions at their own convenience, taking into consideration the tight schedules of the respondents' own work demands. As this research study encountered sensitive issues, the use of sending the questions by email also permitted freedom of expression and the avoidance of gender bias while providing the much-needed objective data. The respondents were given the choice of the specific form of interview, either through face-to-face conversation, telephone call, video call or email as suited to their availability and circumstances.

[33] Craig D. Murray and Judith Sixsmith, 'Email: A Qualitative Research Medium for Interviewing?', *International Journal of Social Research Methodology*, 1(2) (1998), 103 – 121, p. 104.

[34] Craig D. Murray and Judith Sixsmith, p. 107.

Table 1: List of Respondents

No.	Name	Country & Organization	Position	Form of Interview	Date of Interview
1.	(Islamic Expert 1)	Malaysia	- Former Mufti, Malaysia - Former members of Shariah Expert Panel, Department of Islamic Development Malaysia	Face to face conversation	27 August 2015
2.	Dato' Dr. Zulkifli Mohamad Al-Bakri	Office of the Mufti of Federal Territory, Malaysia	- Former Mufti of Federal Territory - Former member of Shariah Expert Panel, Department of Islamic Development Malaysia - Currently Minister in the Prime Minister's Department	Email	25 March 2016
3.	(Islamic Expert 2)	Malaysia	- Senior Lecturer in Islamic Law - Former member of Shariah Expert Panel, Department of Islamic Development Malaysia	Telephone Conversation	21 January 2016
4.	Dato' Dr. Mohd Izhar Ariff Mohd Kashim	National University of Malaysia	Senior Lecturer of Shariah Department (Fiqh of Consumerism and Contemporary Fatwa)	Telephone Conversation	13 January 2016
5.	Dato' Dr. Abdul Rahman Osman	Office of the Mufti of Pahang, Malaysia	- Mufti of Pahang, Malaysia - Former member of Shariah Expert Panel, Department of Islamic Development Malaysia	Telephone Conversation	27 February 2016
6.	Dr. Syed Sikandar Shah Haneef	International Islamic University of Malaysia	Professor of Islamic Jurisprudence	Email	28 May 2016
7.	Dr. Fatris Bakaram	Office of Mufti, The Islamic Religious	Former Mufti of Singapore	Face to face conversation	23 March 2017

No.	Name	Country & Organization	Position	Form of Interview	Date of Interview
		Council of Singapore (MUIS)			
8.	KH Asrorun Ni'am Sholeh	The Council of Indonesian Scholars (MUI) and Syarif Hidayatullah Islamic University, Jakarta, Indonesia	- Secretary to Fatwa Commission, MUI - Senior Lecturer in Islamic Studies	Face to face conversation	25 September 2017
9.	KH Endy Muhammad Astiwara	The Council of Indonesian Scholars (MUI) and Syarif Hidayatullah Islamic University, Jakarta, Indonesia	- Member of Fatwa Commission, MUI - Member of National Shariah Board, MUI - Auditor of Internal Halal Guarantee System, Food and Drug Research Institute - Senior Lecturer in Islamic Studies	Face to face conversation	25 September 2017
10.	H. Ismail Sulaiman MA	Director General Guidance for Muslim Society, Ministry of Religious Affairs, Indonesia	- Head of Islamic Education and Development Division	Face to face conversation	26 September 2017
11.	Assoc. Prof. Dr. Ani Amelia Zainuddin	Chancellor of Tuanku Muhriz Hospital, National University of Malaysia	- Consultant of Paediatric and Adolescent Gynaecology.	Skype conversation	20 July 2016
12.	Dr. Faridah Abu Bakar	Ministry of Health, Malaysia	- Director, Family Health Development Division.	Email	8 September 2016

No.	Name	Country & Organization	Position	Form of Interview	Date of Interview
13.	Dr. Roziana Ariffin	Kuala Lumpur General Hospital Malaysia	- Consultant Clinical Cytogeneticist - Head of the Genetics Laboratory Kuala Lumpur Hospital	Email	9 September 2016
14.	Assoc. Prof. Dr. Muhammad Yazid Jalaludin	University of Malaya Medical Centre, Malaysia	- Consultant Paediatrician - Paediatric Endocrinologist	Telephone Conversation	17 September 2016
15.	Assoc. Prof. Dr. Rahmah Rasat	Chancellor of Tuanku Muhriz Hospital, National University of Malaysia	- Paediatric Endocrinologist	Telephone Conversation	1 August 2016
16.	Assoc. Prof. Dr. Wan Salwina Wan Ismail	Chancellor of Tuanku Muhriz Hospital, National University of Malaysia	- Child and Adolescent Psychiatrist	Email	19 August 2016

Following the approval from the Ethics Committee of the University, an application for an interview, including participant information sheet and a set of semi-structured questions was sent to each interviewee for approval. The local language, i.e. the Malay language was used as the medium of the communication, except for one of the Islamic scholars who is English native speaker. Face to face interviews were conducted with respondents from Singapore and Indonesia. One of the medical experts requested for a Skype conversation and the others chose a telephone conversation or email.

All verbal communications, i.e. face to face, telephone and video call, were recorded via tape recorder, application of Call Recorder ACR and Evaer for Skype application, respectively. The data were transcribed, translated and approved by an independent qualified translator to ensure the accurate meaning of the conversation. While data of email did not require transcription, the response in Malay were translated into English and was approved by the qualified translator as well. Recorded interview sessions were kept secure and highly protected from hardware failure and to ensure data protection. The interview sessions were conducted in a very respectable manner in order to ensure that the sensitive issues related to sex and gender were ethically observed.

1.6.1.2. Document

The second method of data collection was through document. In undertaking case study research, documentation can play the most important role.[35] In a conventional approach, documents entail various types such as agendas, announcement, minutes of meetings, formal study evaluations, news clippings and others. Given that the interpretive framework of this research is Islamic law, the most important sources of reference were the Qurʾān and Ḥadīth. Sharan B. Merriam and Elizabeth J. Tisdell mentioned that it is important to determine the authenticity and accuracy of written documents including its origins and reasons for being written, its author, and the context in which it was written.[36] In this case, the first source is undeniably authentic as it is recognized as definitive proof (*qatʿiy al-thubūt*) in Islamic law. While the latter

[35] Robert K. Yin, p. 174.

[36] Sharan B. Merriam and Elizabeth J. Tisdell, *Qualitative Research*, (San Francisco: Jossey-Bass, 2016), p. 176.

source is speculative proof (*zanni al-thubūt*), and thus *takhrīj al-ḥadīth*, a method of validating the chain of transmitters and grading the authenticity level has been applied. Additionally, information from classical juridical books and religious decree or fatwas, either accessed online or through written materials, was referred to. A careful study of writings was conducted, relying largely on the Sunni juridical perspective within its four schools of thought, with special attention accorded to that of the Shāfiʿī school as the *mazhab* that is widely practised in the three regional countries studied in this research.

Articles and journals of medical information were collected. On top of that, presentations of DSD cases and minutes of meetings at JAKIM were also used as sources of investigation. The information was collected only to illustrate the complexity of the cases as supporting evidence to the general idea of DSD. That is why they were not collected as the first-hand information from the patients or doctors. Doing so would have added another two layers of Ethics Committee approval by each hospital that holds the cases in addition to the approval from the Ethics Committee of UWTSD. Alternatively, the research required the approval of Director General of JAKIM to assess cases that were forwarded to the department by physicians. The approval is recorded in Appendix A. In line with the ethical code of conduct of the medical practitioners, no personal background information of any patient was exposed to the other party, i.e. members of meeting or JAKIM's officers when the cases were presented. Hence, the information about the patient was either unavailable, or, if any, it was kept anonymous due to rights of the patients and confidentiality. Further detail of JAKIM's role in managing patients with DSD will be elaborated along the discussion in this research.

1.6.2. Data Analysis

Content analysis has its roots in religious studies and can be traced to 18th-century.[37] Inductive content analysis has been used for the examination of ideas advanced by classical and contemporary scholars based on written materials. Careful comparisons have been made between data from the medical viewpoint and from the Islamic studies' framework, in each identified subject. Krippendorff explains that texts are not

[37] Chad Nelson, p. 110.

'reader-independent'. The texts are subject to a researcher's perspective and choice of operational definitions. They are not discovered, according to Chad Robert H. Woods, but constructed through the act of interpretation. In this sense, the theoretical framework of Islamic law or *Tawḥīdic* paradigm is interpreted and extended via Islamic jurisprudence (*fiqh*).[38] In Islamic law studies, scholars have developed a specific discipline to analyse the sources of Islamic law, which is known as the principles of Islamic jurisprudence (*ʾuṣūl al-fiqh*). These principles are established rules developed by Islamic scholars in interpreting and deducing rulings form the sources of Islamic law aiming at being justice in interpreting the Divine revelation and avoiding self interest in the process of analysis. Although they are used in the discipline of Islamic studies, the same method is also applicable in a research methodology.

Contemplation of all views and preferences from both opponents and proponents of the medical profession were then subject to analysis based on the techniques and principles of Islamic jurisprudence (*uṣūl al-fiqh*). Although acknowledging and respecting classical Islamic scholars' views, it does not limit the ability to develop ideas and to come up with new findings. Exploration using the main sources of sharīʿah, i.e. the Qurʾān and Ḥadīth, has been made to ensure its flexibility and elasticity regarding current medical advancement and technology.

However, this multi-disciplinary research found its own challenges in seeking relationship between Islamic and medical fields. Whilst the interviews' data provided better perspectives on cross cultural and political insights of the management of patients with DSD, the documents' data provided more extensive perspectives on the relationship between classical Islamic approach and contemporary biomedical perspectives. The interviews provided a primary response to the first and second objectives of this research. Therefore, the findings from this data set of interviews were found to be less relevant to a discussion of the relationship between Islamic and medical aspects as presented in Chapter 3, 4 and 5, which were arranged to answer to these first objectives. However, rich information was obtained from the respondents' opinions and knowledge in responding to the third objective of this research, i.e., in decision-making process and determining the need of the involvement of Muslim

[38] Waseem Gul, p. 91.

scholars in multidisciplinary teams in managing patients with DSD as presented in Chapter 6 and 7. More explanations will be provided on the structure of this thesis in the context of the research objectives at the end of this chapter.

This topic is rarely discussed as a cross-disciplinary research by both the Islamic scholars and medical practitioners. It indicates that exploring DSD from the Islamic perspectives is a novel and under-researched topic. To anaylse further the connection between *khunūthah* and DSD from Islamic perspectives requires detail examination of data that were collected from documented sources, i.e., the Qurʾān and Hadīth. An analysis technique based on the principles of Islamic jurisprudence contributed to the findings of the key connection between the interrelated subjects of Islam and medicine.

To ensure reliability, several methods were used, especially as related to medical information. One of them was peer debriefing in which some of the medical material collected was referred to a medical expert, Sabah Alvi, a Consultant Paediatric Endocrinologist at Leeds Children Hospital, United Kingdom. Another was by informant checks were used in which data was presented again to the respondents to ensure its accuracy. The researcher's professional engagement and experience in the focus group were also employed in ensuring rigorous analysis and theory generation. Besides, in analysing local context within the discussion, the researcher's perspective as an insider observant was applied.

1.6.3. Challenges in Collecting Data

Throughout conducting this study, the researcher encountered several challenges. The notable challenge is the DSD itself which is a very sensitive area, especially for non-medical experts as it encompasses issues on sexual organ development. Another difficulty was that most of the respondents were males, whereas the researcher is a female, and that could be a barrier for detailed discussion which might cause the respondents to become upset or embarrassed when confronted with DSD. In order to avoid any potential risk, both expected and unexpected, the researcher prepared herself with the correct understandable words, especially for medical terms**,** to ensure that the interview sessions could be done in perfect intellectual mode. However, all

respondents gave positive cooperation and responded to the questions with care and accuracy.

The second challenge found was that there are very few Islamic experts among muftis and academicians who have good exposure to DSD or medical issues of gender ambiguity. Most of them have good knowledge of *khunūthah* and the rulings of *khunthā* (*fiqh khunthā*) such as inheritance, prayer and marriage. However, they have little understanding of current medical findings on sex ambiguity, its consequences on the Islamic rulings and the management of patients with DSD. Even the Mufti of Singapore admitted that if he was asked about this subject, he would probably forward it to Malaysia. The same situation was found in Indonesia. Both countries focus more on issues of transsexuals, rather than hermaphrodite. They admitted that they could only respond at their level best because DSD or medical context of sex ambiguity are not their expertise. This scenario is elaborated further in Chapter 7.

Thirdly with regard to the misconception of religious studies on DSD, an explanation on the research background, its issues and objectives were circulated prior to the list of questions. Given the interviewee is a medical practitioner, it was highly believed that the use of the term of DSD is a clear subject. However, referring to the feedback of Ministry of Health Malaysia, the interviewee consistently correcting the use of the terminology leading towards the understanding of the condition of transsexuals and transgender. Perhaps, the reason is due to twofold; i) it is due to high commitment of the interviewee with JAKIM's officer in handling the issue of LGBT, and ii) little is known on the involvement of religious officer or researcher from religious studies in the issue of DSD. Yet, the researcher abled to explain to the officer in charge pertaining to the core context of the research and better feedback was received.

The fourth challenge was that the initial plan of conducting this research was to analyse case studies that had been forwarded to JAKIM by a hospital, i.e. the Chancellor Tuanku Muhriz Hospital, the National University of Malaysia. However, several stages were necessary to get this permission. The Guidelines for Ethical Review of Clinical Research or Research Involving Human Subjects issued by the Medical Review and Ethics Committee (MREC), Ministry of Health, Malaysia, are strict. Yet, exemption from restriction is given when the research or data collection is

based entirely on data abstraction from existing medical or laboratory record; with no interaction with human subject concerned; and with no collection of identifiable private information. In order to get the exemption, this research proposal had to be submitted and registered at Chancellor Tuanku Muhriz Hospital and presented at two meetings, namely Chancellor Tuanku Muhriz Hospital research committee and its medical research committee. The application incurred a cost amounting to RM1,000 (estimated about £200) for an external applicant who is not a member of staff or student at this tertiary hospital. Considering this delicate process, this research focuses on the data collected from JAKIM as to indicate few examples of the management of patients with DSD.

1.7. Literature Review

1.7.1. Islam and Biomedical Ethics

Medicine, as a part of science, illustrates well the understanding of the relationship between Islam and science. The word *ṭibb* (medicine), an Arabic word, is never mentioned in the Qurʾān. But the relation between Islam and medicine is accessible throughout various aspects of human life in this Holy Book. More often than not, treatment and medical issues are referred to various Ḥadīth as recorded in prominent books of Ḥadīth.[39] Given ethics is inseparable from Islamic teachings, it is hard to deny the fact that ethics had been explored and established in those days. Among the earliest literature found, expressing moral values is *Ṭibb al-Ruḥānī* (Spiritual Medicine) written by al-Rāzī, the physician. Although it is not explicitly related to physical medicine, this spiritual remedy, with an Aristotelian influence, according to him, is essential in order to obtain a better quality of life as it balances between excessive and digressive temperaments.[40]

In the 10th century, another scholarly writing was produced by Isḥāq ibn ʿAlī al-Ruhāwī (d. 4th century of Hijri) particularly on the ethics of a physician, *Adab al-Ṭabīb*. Al-

[39] Brief introduction of revelations in the Qurʾān and Ḥadīth is presented in Appendix B.

[40] Muḥammad ibn Zakariyā Al-Rāzī, *Al-Ṭibb Al-Rūḥānī*, ed. by Abd al-Laṭif Al-ʿAbd (Cairo: Maktabah al-Tuḥfah al-Bashariyyah, 1978), p. 46. This book was first published by Dār al-Kutub al-Miṣriyyah, Cairo in 731CE. It was also published by Library of Britannia and publisher of Vatican, Rome as well as adaptation by Ḥamīd al-Dīn al-Kirmānī in his book, *al-Aqwāl al-Zahabiyyah* (The Golden Words).

Ruhāwī wrote on the values of trustworthiness and faith of the doctor and their ethical conducts; the quest of medical knowledge; the conduct of patients and the public; and the status of the doctor as a professional career.[41] The substance of this book, is molded on foundational Islamic belief, despite it being disputable of the author's religious tradition. It has been proven to be the first book written on Islamic medical ethics.[42]

As knowledge expands, the term bioethics was introduced in Western classical literature when Allen Verhey states the possibility of speaking on a 'bioethics before bioethics.'[43] The term 'bioethics' was first coined in 1971 by a biologist, Van Rensselear Potter in his book, '*Bioethics: Bridge to the Future*.'[44] An extensive amount of literature has been published on bioethics not only exclusively on biomedical problems but also on environmental and public health concerns. Bonnie Steinbock argues that as ethics has been interdisciplinary since its inception, 'theology played a foundational role in its creation'.[45] Furthermore, most of the scholars in bioethics are those who are expert in theology such as Joseph Fletcher, Paul Ramsey and Richard McCormick[46]. Steinbock considered these figures as having been instrumental in the birth of bioethics.[47]

[41] Isḥāq ibn ʿAlī Al-Ruhāwī, *Adab Al-Ṭabīb*, ed. by Murayzin Saʿīd Murayzin ʿĀsīrī, 1st edn (Riyaḍ: Markaz al-Malik al-Fayṣal li al-Buḥūth al-Dirāsāt al-Islāmiyyah, 1991)

[42] Based on his writing, it was argued that al-Ruhāwī reverted to Islam due to his call to believe in Allah for Allah is the Creator of humankind, rejection of being astray from sharīʿah (Islamic law) and holding on to faith to be a devoted doctor. Although there is little evidence showing he was a Muslim, it is in no doubt that he was among *ahl al-zimmah* (non-Muslims who lived under the Islamic reign). See more detail in Isḥāq ibn ʿAlī Al-Ruhāwī, *Adab Al-Ṭabīb*, ed. by Murayzin Saʿīd Murayzin ʿĀsīrī, 1st edn (Riyaḍ: Markaz al-Malik al-Fayṣal li al-Buḥūth al-Dirāsāt al-Islāmiyyah, 1991); Sahin Aksoy, 'The Religious Tradition of Ishaq Ibn Ali Al-Ruhāwī: The Author of the First Medical Ethics Book in Islamic Medicine', *Journal of the International Society for the History of Islamic Medicine,* 3 (2004), 9-11.

[43] Allen Verhey, *Reading the Bible in the Strange World of Medicine* (Michigan: W.B. Eerdmans Pub. Co., 2003), p. 1.

[44] Van Rensselear Potter, *Bioethics: Bridge to the Future* (London: Englewood Cliffs, 1971).

[45] Bonnie Steinbock, *The Oxford Handbook of Bioethics* (Oxford: Oxford University Press, 2007), p. 4.

[46] Joseph Fletcher (1905 – 1991) was a professor on pastoral theology and Christian ethics at Episcopal Theological School. Although he later renounced his belief in God, his thought on ethics and theology are still referred to. See Albert R. Jonsen, 'A History of Religion and Bioethics', in *Handbook of Bioethics and Religion*, ed. by David E. Guinn (Oxford: Oxford University Press, 2006), pp. 42 – 47; Paul Ramsey (1913 – 1988) was an ethicist and served as professor of religion at Princeton University. See Albert R. Jonsen, pp. 47 – 51; Richard McCormick was a Roman Catholic moral theologian. He served as professor at Kennedy Institute of Ethics. See Albert R. Jonsen, pp. 52 – 55.

[47] Bonnie Steinbock, p. 4.

In recent years, discussions on medicine in the Islamic perspective have also covered this essential area. In 1987, Fazlur Rahman, was identified as the first Muslim scholar who used the term bioethics as such and discussed it within the Islamic perspectives in his book *Health and Medicine in the Islamic Tradition*.[48] Just six years before that, Hassan Hathout had already discussed the ethics of physicians on modern biomedical advances. Nonetheless, the term of bioethics was not used at that period, such that his study was referred to as the Islamic Code of Medical Ethics.[49] In 1988, Abul Fadl Mohsin Ebrahim wrote on Islamic ethics as a response to current biomedical issues by relating them to values in Islamic teachings, for instance, the characteristics of Muslim doctors, the purpose of human creation, the purpose of marriage and the sanctity of life.[50]

A question gets to be raised here. Is there Islamic bioethics and is it acceptable to use the expression as 'Islamic bioethics'? Based on a study conducted by Cyril Edwin Tennat on numerous matters of life and death, he concludes that there is an Islamic bioethics and it has already been established distinctively based on Islamic principles and concepts, with its own traditions and history.[51] He therefore defines Islamic bioethics as: bioethics by Muslims, on Islamic principles, intended for Muslims.[52] Perhaps, this definition is to highlight the differences between Western bioethics and Islamic bioethics. Like most other literature by Muslim scholars, Ghaiath Hussein, a bioethicist defines Islamic bioethics as 'a methodology of defining, analysing and resolving ethical issues that arise in health care practices or research based on Islamic moral and legislative sources (the Qurʾān, Sunnah and *ijtihād*) aimed at achieving the goals of sharīʿah Islamic morality (i.e. preservation of the human religion, life, mind, wealth and progeny'.[53]

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[48] Fazlur Rahman, *Health and Medicine in the Islamic Tradition - Change and Identity* (New York: Crossroad, 1987), p. 106.

[49] Hassan Hathout, 'The Medical Profession - an Islamic Perspective', *Journal of Islamic Medical Association of North America,* 20 (1988), 25 – 32, p. 31.

[50] Abul Fadl Mohsin Ebrāhīm, *Biomedical Issues: Islamic Perspective* (Mobeni: Islamic Medical Association of South Africa, 1988).

[51] Cyril Edwin George Tennat, 'Is there an 'Islamic Bioethics'? An Examination of Ways in which Bioethical Issues are Approached within Islam, Illustrated by Reference to Modern Discussions about Matters of Life and Death' (unpublished Doctor of Philosophy, University of Wales, Lampeter, 2011), p. 251.

[52] Cyril Edwin George Tennat, p. 44.

[53] *Professionalism and Ethics Handbook for Residents (PEHR): A Practical Guide*, ed. by James Ware, 1st edn, ed. by Ghaiath MA Hussein, Abdulaziz Fahad Alkaaba and Omar Hassan Kasule (Riyadh: Saudi Commission of Health Specialties, 2015), p. 7.

A considerable amount of literature on Islamic bioethics has been published by Muslim scholars and a few scholars of Islam. Among Muslim scholars, both contemporary Sunni and Shiite experts contribute to these discussions. For instance, Abdulaziz Sachedina is able to examine both Sunni and Shiite ethical-juridical approaches. He found out that while Shiite previously rejected the principle of *maṣlaḥah* (public benefit, one of the tools of principles in Islamic jurisprudence), Sunni's juridical approach using various tools of *uṣūl al-fiqh* (principles of jurisprudence) such as *al-qiyās* (analogical reasoning), *al-raʾy* (sound opinion), *al-istiṣlāḥ* (promoting the good), *al-istiḥsān* (selecting the most beneficial) and *ʿurf* (customs) are able to respond to present medical issues.[54] Nonetheless, as Abdallah S. Daar and A. Binsumeit Al-Khitamy contend, the fundamentals of its bioethical rulings are not different from the Sunni.[55] Notwithstanding, more literature from the Sunni perspective will be utilised in this research since the scope of this study is limited to the legal-practical-Islamic thoughts in the South East Asian region.

Among other scholars who are interested in studying bioethics in the Islamic context, and its applications are Thomas Eich, Jonathan Brockopp and Vardit Rispler-Chaim. Both Eich and Brockopp worked together on producing a compilation of articles on Muslim medical ethics. As they were enlightened about the Arabic term '*adab*' (which means etiquette) in 2006 at the Pennsylvania State University conference on Islam and Bioethics, they agreed on using the term Muslim medical ethics rather than Islamic medical ethics to avoid the perception of only one person's or one source to encompass broad aspects of ethical manners.[56]

Rispler-Chaim contributes numbers of discussions on Islam, ethics and medicine. Her writings indicate her interest in fatwa, apart from other sources of Islamic rulings and

[54] Abdulaziz Abdulhussein Sachedina, *Islamic Biomedical Ethics: Principles and Application*, (New York: Oxford University Press, 2009), p. 62.

[55] Abdallah S. Daar and A. Khitamy, 'Bioethics for Clinicians: 21. Islamic Bioethics', *Canadian Medical Association Journal*, 164 (2001), p. 61.

[56] Jonathan E. Brockopp and Thomas Eich, *Muslim Medical Ethics: From Theory to Practice* (Columbia, S.C.: University of South Carolina Press, 2008), p. 2.

ethics, in defining Islamic medical ethics.[57] Based on her observation, which is solely on *fatāwā* (plural form of fatwa) of Egyptian scholars, she describes Islamic medical ethics as apologetic.[58] The reason is based on the response given by Egyptian muftis to the studied issues which are more likely to be detested by Western cultures and advances. Gary Bunt also contributed to analysing the decision-making process in Malaysia on various issues including medical matters. His comparative study in four different countries, i.e. Malaysia, Singapore, Pakistan and United Kingdom gave a general idea of how Muslims from different part of the world react to medical issues. He discovered that 'dialogues between *ʿulamāʾ* (Islamic jurists) and medical authorities are fraught with the complexities of such Islamic interpretations'.[59]

The past thirty years have seen increased acceptance of secular principles of bioethics as were introduced by Thomas Beauchamp and James Childress. It comprises four principles namely beneficence, non-maleficence, justice and respect for autonomy.[60] Beauchamp and Childress's secular 'Principlism' which emphasizes individual rights for doctors and patients was critically analysed from the Islamic perspective. Although the notion of these four principles can be found in Islamic teachings, there has been little agreement on their foundation and practicality.

Arthur Saniotis's contention that the very root concept of biomedical ethics in Islam lies upon the concept that every creation is inter-related and is dependent on God.[61] The inquisitive nature of Muslims to explore scientific and medical fields, according to Ebrahim is primarily to understand Allah's creation, hence to be closer to the Creator. Therefore, neither the question of nature's exploitation, domination, the exertion to

[57] Vardit Rispler-Chaim, 'Islamic Medical Ethics in the 20th Century', *Journal of Medical Ethics,* 15 (1989), 203-208; Vardit Rispler-Chaim, 'The Right Not to be Born: Abortion of the Disadvantaged Fetus in Contemporary Fatwas', *The Muslim World,* 89 (1999), 130-143; Vardit Rispler-Chaim, 'Contemporary Muftis between Bioethics and Social Reality: Selection of the Sex of a Fetus as Paradigm', *The Journal of Religious Ethics,* 36 (2008), 53-76.

[58] Vardit Rispler-Chaim, Islamic Medical Ethics, p. 206

[59] Gary R. Bunt, 'Decision-making and 'Idjtihad' in Islamic Environments: A Comparative Study of Pakistan, Malaya, Singapore and United Kingdom (unpublished Doctor of Philosophy, University of Wales, Lampeter, 1996), p. 131.

[60] Beauchamp, Tom L., Childress, James F., *Principles of Biomedical Ethics* (Oxford: Oxford University Press, 2001).

[61] Arthur Saniotis, 'Islamic Medicine and Evolutionary Medicine: A Comparative Analysis', *Journal of Islamic Medical Association of North America*, 44, (29 Jun 2012), 1 – 9.

control life and death would not be their aim.[62] Therefore Daar and Khitamy conclude that Islamic bioethics, unlike Beauchamp and Childress's view, is based on duties and obligations, rather than rights, although rights do to a certain extent feature as a call to virtue.[63]

In exploring what really constitutes Islamic medical ethics, Aasim I. Padela asserts that it relies upon two distinct forms which are *adab* and ***sharīʿah***.[64] *Adab* is an Arabic word for ethics which refers to universal virtues, and as such has been viewed from the physicians' side. Meanwhile sharīʿah refers to the Islamic law that is inseparable from ethics or moral value while providing such rulings. Medical *adab* or ethics has been emphasized in classical literature. While, in a contemporary study, *al-Ṭabīb Adabuh Wa Fiqhuh* (Ethics Physician and Its Jurisprudence)[65] a collaborated work of Zuhayr Aḥmad al-Sibāʿī and Muḥammad ʿAli al-Barr, focuses on how philosophically and ethically a physician should behave. The distinctive essence of this writing is that it gives attention to the relationships between a physician with patients and with the communities.

Sharīʿah which is also referred to as ***sharīʿah al-islāmiyyah*** is understood as Islamic law. This is the second form indicating Islamic medical ethics. Al-Shāṭibī (d. 790 AH/1388 CE), one of the foundational scholars of Islamic jurisprudence, who popularized the term ***maqāṣid al-sharīʿah*** (the objectives of Islamic law), mentioned that sharīʿah is nothing but a state of providing righteousness for God's servants in this world and the next.[66] Based on the Qurʾanic text, he sees sharīʿah regulations as a guide to the deliberate fulfilment of good (*maṣlaḥah*) and the avoidance of mischief (*mafsadah*).[67] Though al-Shāṭibī never explicitly related this understanding to medical issues in practice, this classical-divine based theory influences, directly or indirectly, major contemporary experts' view on Islam and bioethics such as Ebrahim, Omar

[62] Abul Fadl Mohsin Ebrahim, *Biomedical Issues – Islamic Perspective* (Mobeni: Islamic Medical Association of South Africa, 1988), p. 13.

[63] Abdallah S. Daar and A. Khitamy, p. 61.

[64] Aasim I. Padela, 'Country Report: Islamic Ethics: A Premier', *Bioethics*, 21 (2007), 169-178.

[65] Zuhayr Aḥmad al-Sibāʿī and Muḥammad ʿAli al-Barr, *al-Ṭabīb Adabuh wa Fiqhuh (Ethics of Physician and Its Jurisprudence)*, (Damascus: Dār al-Qalam, 1993).

[66] Ibrāhīm ibn Mūsā al-Shāṭibī, *al-Muwāfaqāt fī ʾUṣūl al-Sharīʿah*, ed. by. ʿAbdullah Darrāz, ʿAbd al-Salām ʿAbd al-Shāfī Muḥammad, vol. 3, (Saudi Arabia: Wizārah al-Shuʾūn al-Islāmiyyah wa al-Awqāf wa al-Daʿwah wa al-Irshād, n.d.), p. 4.

[67] Ibrāhīm ibn Mūsā al-Shāṭibī, vol. 2, p. 23.

Kasule, Padela, Sachedina, Hassan Chamsi-Pasha, Farhat Moazam and Mohammed Ali Albar.[68] They build their framework based on legal juridical approach as what has been defined by Hussein within the comprehension of scriptural texts (the Qurʾān and Ḥadīth) and *ijtihād* (legal independent reasoning) aiming to preserve the principles of *maqāṣid al-sharīʿah*. These principles also shaped Amana Raquib's objectives-oriented Islamic ethics and S. M. Saifuddeen and his colleagues' 'versatile' framework of *maqāṣid al-sharīʿah* on conventional bioethics.[69] They all agreed that the goal of medical treatment ethically must be to preserve the five principles in *maqāṣid al-sharīʿah* viz. faith, life, mind, offspring and property.

Tariq Ramadan, on another occasion, proposes a more radical and complex reforms of the principles of 'Higher Objectives' of the sharīʿah. He stated in his book, *Radical Reform: Islamic Ethics and Liberation* that the five – or six for other classical scholars – higher objectives of sharīʿah are not sufficient.[70] He therefore lists twelve foundational principles transcended from three elements that are life, nature and peace which found their basis in a global conception of life and death as well as common good and interest.[71] Those foundational principles are promoting and protecting dignity, welfare, knowledge, creativity, autonomy, development, equality, freedom, justice, fraternity, love, solidarity and diversity.[72] They are the essentials in establishing applied ethics within three groups namely, the inner being, the being (individual) and societies and groups. This concept of Islamic ethics was later used to translate ethical issues with regard to biomedical advances and public health.

[68] Abul Fadl Mohsin Ebrahim, *Biomedical Issues - Islamic Perspective* (Kuala Lumpur: A.S. Nordeen, 2005)., Omar Kasule, *The Legal and Ethical Basis of Medical Practice,* Workshop on use of Ijtihad Maqasidi for Contemporary Ethico-Legal Problems in Medicine, (Hyderabad: Fiqh Academy of India, 3 – 4 February 2007)., Aasim I. Padela, 'Country Report: Islamic Ethics: A Premier', *Bioethics*, 21 (2007), 169-178., Abdulaziz Abdulhussein Sachedina, *Islamic Biomedical Ethics Principles and Application,* (Oxford; New York: Oxford University Press, 2009)., Farhat Moazam, 'Sharia Law and Organ Transplantation: Through the Lens of Muslim Jurists', *Asian Bioethics Review,* 3 (2011), 317., James Ware, , Hassan Chamsi-Pasha and Mohammed Ali Albar, 'Western and Islamic Bioethics: How Close is the Gap?', *Avicenna Journal of Medicine,* 3 (Jan - Mar 2013), 8-14.

[69] S. M. Saifuddeen and others, 'Maqasid Al-Shariah as a Complementary Framework to Conventional Bioethics', *Science and Engineering Ethics,* 20 (2014), 317-327.

[70] Tariq Ramadan, *Radical Reform: Islamic Ethics and Liberation* (Oxford: Oxford University Press, 2009), p. 128.

[71] Tariq Ramadan, *Radical Reform*, p. 144.

[72] Tariq Ramadan, *Radical Reform*, p. 140

In general, Bargher Larijani and Farzaneh Zahedi Anarki observe that components and mechanisms in Islamic law make it flexible to suit itself to newly emerged queries or to be adaptable with contemporary issues especially on biomedical issues.[73] Henk Ten Have adds that values in Islam have been seen to be commonly shared among all human beings.[74] The efforts of Muslim scholars reached the international level when it was referred to in drafting the Universal Declaration on Bioethics and Human Rights.[75] However, Sachedina contends that the theological ethical underpinning is less focused in juridical decisions in current debates of newly emerging biomedical issues within the Muslim world.[76] Corresponding to the current discussion on Islamic (bio) ethics, this research will find its ground in a sharīʿah framework as it was traditionally developed by the classical scholars and is presently studied within cultural and contextual settings. This emphasis is because sharīʿah comprises both juridical and ethical dimensions and it has sounds parameters in preserving human health.[77]

1.7.2. Islam and Biomedical Issues

Numerous studies have attempted to explain the Islamic legal and ethical approaches to a number of biomedical issues ranging from matters of life to death in different countries, cultures and period of time. Issues on reproduction, such as in-vitro fertilization, artificial insemination, sperm donors, surrogate motherhood, contraception, therapeutic cloning and research on stem cells can be found in plenty Islamic literature.[78] Furthermore, issues on paediatrics have also been carried out, for instance on lactation and milk banks related to the verse of the Qurʾān and the numbers of *Aḥādīth* and how it balances between the nutritional needs of a baby and

[73] Bargher Larijani and Farzaneh Zahedi Anaraki, "Islamic Principles and Decision Making in Bioethics", *Nature Genetics,* 40 (2) (2008), 123; Abdulaziz Sachedina, p. 45.

[74] Henk ten Have, 'Global Bioethics: Transnational Experiences and Islamic Bioethics', *Zygon,* 48 (2013), p. 613.

[75] Henk ten Have, p. 613.

[76] Abdulaziz Abdulhussein Sachedina, p. 8.

[77] Abdulaziz Abdulhussein Sachedina, p. 224.

[78] Abul Fadl Mohsin Ebrahim, Biomedical Issues, p. 93; Ahmed Abdel Aziz Yacoub, p. 70; Cyril Edwin George Tennat, p. 109; Jonathan E. Brockopp and Thomas Eich, Muslim Medical Ethics; Abdulaziz Abdulhussein Sachedina, p. 103; Thomas Eich, 'Decision-Making Process among Contemporary 'Ulama': Islamic Embryology and the Discussion on Frozen Embryos', in *Muslim Medical Ethics from Theory to Practice*, ed. by Jonathan E. Brockopp and Thomas Eich (Columbia: University of South Carolina, 2008), 2, pp. 61-77; Sushi Krehbeil Keefe, 'Competing Needs and Pragmatic Decision-Making: Islam and Permanent Contraception in Northern Tanzania', in *Muslim Medical Ethics from Theory to Practice*, ed. by Jonathan E. Brockopp and Thomas Eich (Columbia: University of South Carolina, 2008), 3, pp. 101-117.

milk kinship in a family.[79] To add the most confronted issues in medicine and ethics over recent decades are those related to the termination of life including abortion, euthanasia and brain death.[80] If the act of terminating one's life is necessary in order to save another life, organ donation and transplantation cannot be left out during discussions.[81]

Public health related issues which have become pandemic at societal level such as drug addiction and AIDS as well as efforts to reduce its harm have also been discussed encompassing the questions on the treatment and patients' management from Islamic underpinnings.[82] Vaccination and female genital mutilation are other important examples that occur in Islamic discourses.[83] Genetic engineering, pre-implantation genetic diagnosis and sex assignment surgery are among other issues related to gender that have been studied from the Islamic perspective.[84] Sachedina in discussing issues related to cosmetic surgery highlights his concern about hermaphrodites in which the identity of individual personhood is a matter needing attention especially regarding ritual religious obligations and social life.[85] Mohd Salim Mohamed and Siti Nurani Mohd Nor wrote on Islamic ethics with regard to sex assignment surgery on newborns with Disorders of Sex Development (DSD), which is the condition that will be studied further in this research. Both of them base their argument on the concept

[79] Munawar Ahmad Anees, *Islam and Biological Futures* (London: Mansell Publishing Limited, 1989), p. 119; Taqwa Zabidi, 'Penubuhan Bank Susu Ibu Di Malaysia: Satu Analisis Hukum (Establishment of Human Milk Bank in Malaysia: An Islamic Ruling Analysis)', *Jurnal Penyelidikan Islam,* 25 (2012), 17-25; Afif El-Khuffash and Sharon Unger, 'The Concept of Milk Kinship in Islam: Issues Raised when Offering Preterm Infants of Muslim Families Donor Human Milk', *Journal of Human Lactation,* 28 (2012), 125-7.

[80] Abul Fadl Mohsin Ebrahim, 'Islamic Ethics of Life: Abortion, War and Euthanasia', *Journal of Islamic Studies,* 16 (2005), 153; Jonathan E. Brockopp, *Islamic Ethics of Life : Abortion, War, and Euthanasia* (Columbia, S.C.: University of South Carolina Press, 2003); Tariq Ramadan, p. 168; Abdulaziz Abdulhussein Sachedina, p. 128; Vardit Rispler-Chaim, The Right Not to be Born, p. 130; Cyril Edwin George Tennat, p. 138; Norchaya Talib, *Euthanasia – A Malaysian Perspective* (Selangor: Sweet & Maxwell Asia, 2002), p. 7; Kiarash Aramesh and Heydar Shadi, 'Euthanasia: An Islamic Ethical Perspective', *Iranian Journal of Allergy, Asthma and Immunology,* Suppl 5 (February 2007), 35-38; Islamic Organization of Medical Sciences, *Overview of Islamic Organization of Medical Sciences* (Kuwait: Al-Ressala Press, n.d.).; Aḥmad Muḥammad Kanʿān, *Al-Mawsūʿah Al-Ṭibbiyyah Al-Fiqhiyyah (the Encyclopaedia of Medical Jurisprudence)*, 2nd edn (Beirut: Dār al-Nafāʾis, 2006), p. 780; Muḥammad ʿAlī Jumuʿah, *Al-Kalām Al-Ṭayyib Fatāwā Miṣriyyah* (Cairo: Dār al-Salām, 2007), p. 306.

[81] Abdulaziz Abdulhussein Sachedina, p. 174

[82] Mansur Ali, 'Perspectives on Drug Addiction in Islamic History and Theology', *Religions,* 5 (3) (2014), 912-928, p. 924 – 925.

[83] Gerard Molleman and Lilian Franse, 'The Struggle for Abandonment of Female Genital Mutilation/Cutting (FGM/C) in Egypt.', *Global Health Promotion,* 16 (2009), 57-60., Munawar Ahmad Anees, p. 47.

[84] Vardit Rispler-Chaim, The Right Not to be Born, p. 53, Abdulaziz Abdulhussein Sachedina,

[85] Abdulaziz Abdulhussein Sachedina, p. 193.

of *maqāṣid al-sharīʿah* and *maṣlaḥah*. However, kindly take note that this study fails to examine other sources of sharīʿah and is limited to the issue of surgery.

Without any need to discuss further details on every medical concern here, the above lists are sufficient to indicate that a large and growing body of literature has investigated abundant medical issues from the Islamic perspective. There is a need to move beyond the issues of reproduction, termination of life and organ donation.[86] The studies of Mohamed and Mohd Nor on DSD is a good starting point to be explored further in this research. The next subtopic will feature the gap that will be filled up through this study.

1.7.3. Islam and Disorders of Sex Development (DSD)

Disorders of Sex Development (DSD) is one of medical conditions that raise a number of questions from different perspectives including biomedical science, human rights, cultural discourses and religious standpoints.[87] More often than not, DSD is understood in the generality of various gender issues despite the fact of its biological physiognomies. Saskia E. Wieringa asserts that different scopes of considering any case would open up different legal impacts.[88] Hence, a right definition within specific criteria would help to resolve the issues with the best solution.

In 1975, the first issue on sex change appearing in Malaysia's mainstream media drew long discussions among Muslim scholars and the public. Kartina binti Abdul Karim who previously was a man was married to Abdul Razak Othman at the Johore Religious Department, one of the state Islamic departments in Malaysia.[89] Datuk Syed Alwi, the Vice Mufti of the state gave approval for their marriage. But a few muftis from other states advised Alwi to revise his decision. The spouse was reported to have expressed his wish to continue with their married journey as a happy family.

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[86] Maria C. Inhorn, 'Conclusion', in *Muslim Medical Ethics from Theory to Practice*, ed. by Thomas Eich and Jonathan E. Brockopp (Columbia: University of Carolina Press, 2008), pp. 252-255.

[87] Saskia E. Wieringa, 'Gender Variance in Asia – Discursive Contestations and Legal Implications', *Gender, Technology and Development*, 14(2) (2010), 143 – 172.

[88] Saskia E. Wieringa, p. 145. Wieringa also explains this issue from the perspective of Indonesian Muslim groups when she elaborates further on the human rights aspect.

[89] Guntor Sadali, 'Kahwin Lepas Tukar Seks (Marriage After Sex Change)', *Berita Harian*, 7 November 1975, Front Page, p. 1.

In 1988, Sayyid ʿAbd Allah or later known as Sally, who successfully underwent a sex change surgery and felt satisfied with it, suffered from a judicial implication as the al-Azhar University, Cairo took this case to the courts.[90] Although this case was neither the first nor the last in Egypt's history, this particular case attracted huge interest in public debates including religious, biomedical and legal discussions.[91]

The story of Alterina Hofan, a transgendered Indonesian who was charged with identity fraud in 2010, raised awareness of how future similar cases should be investigated.[92] On another occasion, Wong Chiou Yang and Mohd Ashraf Hafiz Abdul Aziz, Chinese and Malay Malaysian citizens respectively, failed to get the court's permission to change their gender status due to lack of biological evidence; even though they had had sex change surgery already.[93]

The story of Abdul Aziz turned out to become all the more tragic because it is believed that this case that caused him to die. He suffered heart problems and low blood pressure following the court's rejection of his application. The list of stories continues, but little remedial efforts, if any, from the religious academic perspective have been put into effect. The question of whether those cases were related to an increase in the number of reported biological disturbances remains unanswered.

'Transgender' can be broadly divided into two types of factors, psychology and biology. The former demonstrates the group of people also known as effeminate, psycho-

[90] Jakob Skovgaard-Peterson, 'Sex Change in Cairo: Gender and Islamic Law', *The Journal of the International Institute*, 2(3) (Spring 1995), pp. 1 – 2.

[91] Jakob Skovgaard-Peterson, p. 2; Paula Sanders, 'Gendering the Ungendered Body: Hermaphrodites in Medieval Islamic Law', *Women in Middle Eastern History - Shifting Boundaries in Sex and Gender*, ed. by Nikki R. Keddie and Beth Baron (New Haven and London: Yale University Press, 1991), 74-95; Azza Khattab, 'Sally's Story', *Egypt Today*, 25(7)(July 2004) [Online]. Available at <http://ai.eecs.umich.edu/people/conway/TSsuccesses/Sally%20Mursi/Sally's%20story%20-%20The%20Magazine%20of%20Egypt.htm> [accessed 18 August 2015]; Mohamed Jean Veneuse, 'The Body of the Condemned Sally: Paths to Queering anarca-Islam', *Anarchist Developments in Cultural Studies*, 2010(1), 1 – 16, [Online]. Available at <http://theanarchistlibrary.org/library/mohamed-jean-veneuse-the-body-of-the-condemned-sally-paths-to-queering-anarca-islam> [accessed 18 August 2015].

[92] Ika Krismantari, 'Alterina Latest Proof of Transgender Problems', *The Jakarta Post,* 14 May 2010 [Online]. Available at <http://www.thejakartapost.com/news/2010/05/14/alterina-latest-proof-transgender-problems.html> [accessed: 17 August 2015].

[93] Munaarfah Abu Bakar, 'Mahkamah Tolak Permohonan Wanita Jadi Lelaki', *Berita Harian*, 5 November 2004, p. 8.

sexual, mixed-sex or transsexual persons.[94] They are the ones who have Gender Identity Disorder (GID) and are psychologically inconsistent with the assigned sex accorded to them at birth.

On the other hand, from the medical context, focus is given to the second type in which sex development is disturbed from an early age. Commonly, known as hermaphrodites and eunuchs, they are ostracized by society. However, those terms are contentious and controversial to the point of even giving even more feelings of hurt and harm to the patients and families. Until new terminologies get to be introduced, 'Disorders of Sex Development' (DSD) has been replacing those terms academically[95]. Notably, this is the focus of this research in relation to the Islamic underpinnings. Due to time constraints, this research will focus mainly on Islamic perspectives upon DSD conditions. Further research is needed to explore the Islamic perspective on GID cases, particularly in respect to the impact on the social life of the people affected.

1.7.4. Nomenclature: *Khunthā* and DSD

The research and discussions about DSD in the medical field are undeniably extensive in various aspects. However, less research attention has been given to the Islamic point of view, even though it is very significant to Muslim communities. DSD as an umbrella term of many different diagnoses is defined as a congenital condition in which the development of chromosomal, gonadal or anatomical sex is atypical.[96] Broad definitions covered by this terminology have been accepted by consensus among medical practitioners. There are four classifications with regard to chromosomal factors which are XX-DSD, XY DSD, ovotesticular DSD and gonadal dysgenesis.[97]

[94] Noraini Mohd Noor and others, *Sexual Identity Effeminacy among University Students* (Kuala Lumpur: International Islamic University Malaysia, 2005), p. 1.

[95] I. A. Hughes, 'Disorder of sex development: A New Definition and Classification', *Best Practice and Research Clinical Endocrinology & Metabolism*, (2008) 119 – 134, (p. 120).

[96] I. A. Hughes, p. 120; Consortium on the Management Disorders of Sex Development, *Clinical Guidelines for the Management of Disorders of Sex Development in Childhood* (North America: Accord Alliance, 2006), p. 2. Gonad is a male or female reproductive organ that produces the gametes. It is also known as ovary and testis.

[97] Rabah M. Shawky and Sahar M. Nour El-Din, p. 198.

In Islam, male and female are the two recognized genders as stated in the Qurʾān.[98] However, there is a group of people that falls between these two genders. Al-Qurṭubī (d. 671 AH/ 1273 CE), a *mufassir* (Qurʾanic commentator) explains that this is not a third gender, but it is originally referred to either male or female, known as *khunthā*.[99] Ibn Qudāmah (d. 620 AH/1223 CE), a prominent Muslim scholar in the 12th century, explains that *khunthā* refers to a person who has either both penis and vagina or merely a hole for urinating at the vaginal part.[100] He divided *khunthā* into two categories, which are *khunthā mushkil* (intractable) and *khunthā ghayr mushkil* (discernible)[101], also known as *khunthā wāḍiḥ*.

There are three physical conditions according to al-Sibāʿī and al-Barr; firstly, the one who has neither vagina for female nor penis for male, leaving one orifice for urinating. Secondly, it refers to a person born with neither type of genitals nor anus but there exists an orifice for urinating and defecating. Thirdly, the worst condition of a person born with none of the organs but tends to vomit out digested food.[102] Apart from that, a contemporary scholar has widened the definition of *khunthā* as stated by Aḥmad Muḥammad Kanʿān by looking into the chromosomal factor.[103] The omission, addition or mixing of chromosomes have been included as an element in defining *khunthā*. Zaliha Tak also suggests that *khunthā* occurs due to chromosomal anomalies.[104] It seems that *khunthā* shares common elements with DSD. Nevertheless, neither Kanʿān nor Tak explain in detail the relation between *khunthā* and various types of DSD.

[98] The categories are mentioned in number of verses such as in *Sūrah al-Nisāʾ* (The Women), 4: 1. When reference is made to the Qurʾanic text, the reference will indicate the name of *Sūrah* (Chapter), number of *Sūrah* and number of verses without the publication as the details of the verse are consistent in all publications. While the translations vary from one to another, the researcher refers to the translation based on ʿAbdullah Yūsufʿ Alī, *The Holy Qur´an Text, Translation and Commentary*, New Revised edn (Brentwood: Amana Corporation, 1989). Self-translation will be mentioned if it is required.

[99] Abū ʿAbdullah Shamsuddin al-Qurṭubī, *Al-Jāmiʿ Li Aḥkām Al-Qurʾān (The Compiler for Qurʾanic Rulings)*, ed. by Hishām Samīr al-Bukhārī vol. 5 (Riyadh: Dār ʿĀlam al-Kutub, 2003), p. 2.

[100] ʿAbdullah ibn Aḥmad ibn Qudāmah, *Al-Mughnī* (Beirut: Dār Aḥyāʾ al-Turāth al-ʿArabiy, n.d.), p. 253.

[101] ʿAbdullah ibn Aḥmad ibn Qudāmah, p. 253.

[102] Zuhayr Aḥmad al-Sibāʿī and Muḥammad ʿAli al-Barr, p. 314.

[103] Aḥmad Muḥammad Kanʿān, *al-Mawsūʿah al-Ṭibbiyyah al-Fiqhiyyah*, ed. 2, (Beirut: Dār al-Nafāʾis, 2006), p. 438.

[104] Zaliha Tak, *Khuntha dan Mukhannath Menurut Perspektif Islam* (Hermaphrodites and Transgender from the Islamic Perspective), (Kuala Lumpur: Jabatan Kemajuan Islam Malaysia, 1998), p. 14.

Indeed, further discussions based on the juridical approach required in order to identify whether the status of *khunthā* can be defined perfectly as DSD or vice versa is necessary. A limited scope of definitions proposed by the classical scholars can be reviewed within the thematic studies of scriptural texts of Islamic sources as this status has a great impact upon Muslims' religious duty and in the social cultural context.

1.7.5. Gender Assignment

A diagnosis aspect is the first step in clinical procedures. The result will lead to gender assignment before treatment takes its place. However, a different method of recognizing 'true' gender is identified for DSD and *khunthā mushkil*. As DSD is based on current biomedical technology, factors other than genitalia functioning are observed, such as genetic, gonadal, phenotypic and psychological sex.[105] Those aspects should be critically analysed in assigning or reassigning a gender based on clinical review.

Meanwhile, Muslim scholars such as Ibn Qudāmah, al-Nawāwī (d. 675 AH/1277 CE), al-Suyūṭī (d. 911 AH/1505 CE) and contemporary scholar, al-Sayyid Sābiq (d. 1420 AH/2000 CE) have described techniques which are physically observed in assigning specific gender for *khunthā.*[106] The main sign is by looking at which organ urine gets to be excreted from and which then is the most functioning organ.[107] If it is uncertain, one has to wait to see the changes during puberty reflecting secondary sexual characteristics either along 'man-lines' or 'female-lines'. The least important sign is psychosexual orientation. It is considered to be referred to only when all other signs are not appropriate.

On the other hand, social and cultural bases have great influence on the decision making process, in addition to medical observation. In Malaysia, empirical observation

[105] Rabah M. Shawky and Sahar M. Nour El-Din, p. 198.

[106] ʿAbdullah ibn Aḥmad ibn Qudāmah, pp. 253-254; Yaḥyā ibn Sharaf al-Nawāwī, *Rauḍah al- Ṭālibīn*, ed. by ʿAdil Aḥmad ʿAbd al-Mawjūd and ʿAlī Muḥammad Muʿawwiḍ, vol. 1, Special edn. (Saudi Arabia: Dār ʿĀlim al-Kutub, 2003), pp. 188 – 190; Al-Sayyid Sābiq, *Fiqh al-Sunnah*, vol. 3, (Beirut: Dār al-Kitāb al-ʿArabiy, 1987), pp. 385 - 386; Jalāl al-Dīn ʿAbd al-Raḥman ibn Abū Bakr al-Suyūṭī, *al-Ashbāh wa al-Naẓāʾir fī Qawāʿid wa Furūʿ Fiqh al-Shāfiʿiyyah (Plausible and Identical in Methodologies and their Branches of Shāfiʿī School of Thought)*, ed. by Muḥammad Ḥasan Muḥammad Ḥasan Ismāʿil, vol. 2 (Beirut: Dār al-Kutub al-ʿIlmiyyah, 2001), pp. 40 – 42.

[107] ʿAbdullah ibn Aḥmad ibn Qudāmah, p. 253.

has been carried out by Ursula Kuhnle and Wolfgang Krahl regarding the cultural impact on gender assignment through a multi-cultural group of DSD patients.[108] It obviously shows that the medical approach is guided more by cultural bias rather than by medical criteria.[109] In other countries, there are reports stating that the male genotype is the preferred gender. For example, in the Kingdom of Saudi Arabia due to financial, social and cultural beliefs, sons are preferred.[110] A similar socio-cultural factor also drives Egyptian society to prefer the male sex rather the female.[111] This standpoint will be discussed further as to what extent the possibility of amalgamation of Islamic jurisprudence, medical rules and cultural factors can be considered.

1.7.6. Sex Assignment Surgery

Sex Assignment Surgery (SAS) has been given much attention by Islamic scholars and juristic councils. Perhaps, it is due to the increasing number of sex change cases merely based on emotional desire that is clearly prohibited in Islam. This prohibition is based on the Qurʾanic verse in *Sūrah al-Nisāʾ* (The Women).[112] There are numbers of fatwa (decrees made by juristic councils or muftis) pertaining to this surgical procedure. For instance, the verdict of the 39th conference of the Council of Senior Scholars in Saudi Arabia expounds on the initial state of prohibition of the sex change. Yet, it is permissible to overcome gender ambiguity when dominant signs prevail. Besides, parents of minor patients should be informed with the result of a medical investigation.[113]

The Fatwa Committee of the National Council for Islamic Religious Affairs, Malaysia discussed the issue regarding sex reassignment surgery during its 25th conference on 13 Disember 1989. Members of the committee agreed that SAS is prohibited for transvestites. However, for those who were born as *khunthā mushkil* it is permissible

[108] Ursula Kuhnle and Wolfgang Krahl, 'The Impact of Culture on Sex Assignment and Gender Development in Intersex Patients', *Perspective in Biology and Medicine*, 45 (1) (Winter 2002), 85 – 103.

[109] Ursula Kuhnle and Wolfgang Krahl, p. 87.

[110] S.A. Taha, 'Male Pseudohermaphroditism: Factors Determining the Gender of Rearing in Saudi Arabia', *Urology*, 43 (3) (1994), 370-374, p. 370.

[111] Rabah M. Shawky and Sahar M. Nour El-Din, p.198

[112] The Qurʾān, *Sūrah al-Nisāʾ* (The Women), 4: 119. This verse states the deeds of Satan in misleading human by several actions including altering Allah's creation. It follows with a reminder to not take Satan as an ally or humans will suffer a great loss in the Hereafter.

[113] Ṣāliḥ ibn Fawzān Al-Fawzān, *al-Fatāwā al-Mutaʿalliqah bi al-Ṭibb wa Aḥkām al-Marḍā* (Fatwas Related to Medicine and Rulings on Patients), (Riyadh: Riʾāsah Idārah al-Buḥūth al-ʿIlmiyyah wa al-Iftāʾ, 2003), p. 305.

to ‘undergo surgery to retain the most functional private part’.[114] A similar decree was also provided by *Majelis Ulama Indonesia* (MUI-the Council of Indonesia Scholar) in its conference held in 2010.[115]

Sachedina affirms that jurists acknowledge all the potential risks of surgical treatment, but corrective surgery would enable the patient to have a proper social sex classification especially within a religious and cultural-gender-differentiation accentuated community.[116] However current debate on medical perspectives focuses on two concerns: i) when is the appropriate timing of the surgery; and ii) who is the eligible person to make decision.

Referring to the former concern, Sayed Sikandar Shah Haneef and Mahmood Zuhdi Abd Majid argue against early surgical intervention for minor patients based on its juridico-ethical implications from Islamic law and ethical perspectives.[117] Mohamed and Mohd Noor propose utilisation of *maqāṣid al-sharīʿah* in resolving the moral dilemma in medical practice, specifically on appropriate timing for conducting SAS for an infant. The elasticity of this concept is viewed as a mechanistic tool in order to prevent misjudgement and to ensure potential benefits outweigh potential harms in the decision making process.[118] However, their elaboration restricts the apparent meaning of *maqāṣid al-sharīʿah* without further exploration on the key elements of this notion. In this instance, this research will elaborate further the discussion within the framework of Islamic bioethics.

Little is known pertaining to the second concern, i.e. the eligible decision makers in managing patients with DSD from the Islamic perspectives. Nevertheless, the discussion from the medical perspectives has grown further even to the extent of proposing the participation of religious leaders in the decision-making process. Ani Amelia and others have conducted a research on Congenital Adrenal Hyperplasia

[114] Department of Islamic Development Malaysia, *Decision of the Fatwa Committee of the National Council for Islamic Religious Affairs Malaysia* (Putrajaya: Department of Islamic Development Malaysia, 2010).

[115] Majelis Ulama Indonesia, *Himpunan Fatwa MUI (Collections of MUI Fatwa)*, ed. by Hijrah Saputra, Andriansyah and Andhika Prasetya K. S.Sos (Indonesia: Erlangga, 2011), p. 605.

[116] Abdulaziz Sachedina, pp. 193 – 194.

[117] Sayed Sikandar Shah Haneef and Mahmood Zuhdi Abd Majid, ‘Medical Management of Infant Intersex: the Juridico-Ethical Dilemma of Contemporary Islamic Legal Response’, *Zygon*, 50 (4)(2015): 809-829, p. 828

[118] Mohd Salim Mohamed and Siti Nurani Mohd Noor, ‘Islamic Bioethical Deliberation on the Issue of Newborns with Disorders of Sex Development’, *Science and Engineering Ethics*, 20 (25 Mar 2014).

(CAH) patients in developing nations including in Malaysia. They identified that poor Quality of Life (QOL) of the patients are affected by late presentation or sequelae, no prenatal treatment or screening, psycho sexual issues, no support group, lack of understanding of the condition and medication, lower economic status, less governmental support for health care spending, religious issues and traditional beliefs, rumours and stigma of being intersex and pressure to select the optimal gender.[119] As a result, the research team recommends that a multidisciplinary team should be formed comprising of medical practitioners from a wide range of specialty, ethicists, support groups and religious leaders in order to ensure a better QOL for patients with DSD.[120] Remarkably, this recommendation highlights the importance of religious leaders to not overlook this issue. Therefore, it increases the need to discuss Disorders of Sex Development within the scope of Islamic studies.

1.8. Structure of the Thesis

This thesis is divided into 8 chapters. This chapter contains the preliminary background of conception of this study, including objectives, scope, methodology and a literature review. Chapter 2 primarily establishes the core framework of the study. A number of assumptions on the relationship between Islam and medical ethics or bioethics were examined to identify the most suitable theoretical framework for evaluating the condition of Disorders of Sex Development (DSD). This chapter proposes sharīʿah as the legal and ethical framework in analysing DSD by employing the principles of Islamic jurisprudence and Islamic legal maxims as to achieve the wide-ranging purposes of sharīʿah.

The following chapters discuss management of patients with DSD in its sequence: beginning in Chapter 3 with a discussion on sharīʿah and medicine, and particularly on the condition of human sexual development. This chapter is explored in order to respond to the first objective of the research, i.e. on the relation between *khunūthah* and DSD. Exploration of gender from hermeneutic study and biological development

[119]Ani Amelia Zainuddin and others, 'Research on Quality of Life in Female Patients with Congenital Adrenal Hyperplasia and Issues in Developing Nations', *Journal of Pediatric and Adolescent Gynaecology,* 26 (December 2013), 296-304.

[120] Ani Amelia and others, p. 302–303.

based on Islamic and medical perspectives, respectively, will increase our insight into common sexual development and its abnormalities. The latter is the main focus of this research. To better understand the Islamic underpinnings of management of DSD, this medical condition will be explored in comparison with the condition of *khunūthah,* as outlined by the classical Islamic scholars. Therefore, identification of their relation is essential prior to a discussion on DSD's management. This chapter also suggests a proposal for redefinition of *khunūthah.* While the classical definition indicates external genital appearance, a new definition considers the biological condition, in order to avoid any misinterpretation of hermaphroditism from an Islamic perspective.

The second objective of this research is to identify bioethical underpinnings of DSD particularly on gender assignment, treatment and decision-making process. These three aspects are analysed in chapters 4, 5 and 6. Chapter 4 covers research into the best approach to gender assignment for different groups of DSD and *khunūthah* (as described in Chapter 3). Five models of gender assignment are examined thoroughly within the framework of Islamic jurisprudence. A novel and holistic Islamic biomedical approach is proposed as a tool for assigning (and reassigning) appropriate gender for affected patients.

Another vital bioethical issue in managing patients with DSD pertains to treatment once the appropriate gender has been identified and assigned. Chapter 5 presents types of available treatment and constant debates related to them prior to the discussion from the Islamic perspectives. Evaluation from the Islamic perspective justifies patient treatment. In response to the current contestation on timing of the treatment due to its harmful effect in later age, the researcher proposes the use of '*maṣlaḥah*' as a mechanistic tool to consider the appropriate timing of medical intervention to prevent detrimental and long-life complications.

While medical intervention may only be conducted pursuant to informed consent, the next issue concerns who can make the decisions. Chapter 6 explores the characteristics of autonomy and competency as the very core components of an eligible decision maker. The historical paradigm of inculcating greater professionalism among doctors in the context of the accommodation of patient rights is examined in light of Islamic teachings. This relies upon identifying the actors, i.e. patients, doctors,

parents and religious leaders, and their roles based on four different approaches of decision making process in the medical settings. The elements of autonomy and competency as elucidated in Islam help establish the most appropriate model of decision-making process in managing DSD.

Subsequent to the explication of the roles of decision makers, Chapter 7 analyses the roles of religious leaders, particularly among religious authorities. This chapter addresses the third objective of this research in determining the need for the involvement of Muslim scholars in multidisciplinary teams to manage patients with DSD. In order to ensure consistency of the data, comparison has been made on this particular topic between three different countries in the South East Asian region, namely Malaysia, Singapore and Indonesia. These countries have been chosen based on certain criteria including holding on Sunni school of thoughts and having common shared values among Malay Muslim communities.

Chapter 8 summarizes this thesis. The evaluation of Sunni Islamic perspectives concerning a medical issue known as Disorder of Sex Development demonstrates the dynamism of Islamic biomedical ethics in resolving issues on gender ambiguity. Eight conclusions are reached, and the findings of this research and several other recommendations have been proposed as a way forward in dealing with this critical and sensitive medical condition.

2. SHARĪʿAH: THE ISLAMIC LEGAL AND ETHICAL JURIDICAL APPROACHES

2.1. Overview

Extensive readings were conducted on biomedical ethics in Islamic perspectives to identify the most appropriate framework for this research. The approaches of deliberating either Islamic ethics or Islamic bioethics or Islamic biomedical ethics vary to one another. In this chapter, those approaches are grouped into three typologies of Islamic biomedical ethics' discourse, i.e. foundation, scopes and actors. The first typology discusses several approaches that focus on the foundation of Islamic bioethics. The second typology is on the ethics itself which emphasizes on the moral conduct of a physician, on medical profession and biomedical issues. Whereas the final typology underscores the actors who are involved in the development of Islamic biomedical ethics.

Regardless of the types of discussions, most scholars construct their argument with reference to the Qurʾān and Ḥadīth. Based on thorough analysis of those three typologies a holistic framework was identified at the end of this chapter as a framework of Islamic perspectives in deliberation of Disorders of Sex Development. This strongly suggests that sharīʿah is a holistic approach that governs the whole concept of Islamic bioethics. It does not only serve the purpose of legal rulings, but also provides moral and ethical manifestations. It also pays more attention on the actors involved in shaping and developing the concept of Islamic biomedical ethics.

2.2. Deliberation of a Bioethical Context

Medical conditions are studied not only from their clinical context but also from the ethical aspect. Therefore, bioethical deliberation comes into discussion. It is essential for us to understand what is meant by 'bioethics'. The term bioethics was coined by a biologist, Van Rensselear Potter in his book, '*Bioethics: Bridge to the Future*' in 1971.[121] However, the discussions on ethics and medicine appeared earlier than this

[121] Van Rensselear Potter, *Bioethics: Bridge to the Future* (London: Englewood Cliffs, 1971).

by the term ‘medical ethics’. The conflicts between medicine and ethics were less common in older times because treatment, medicines and operations were justified by the benefit of individual patients.[122] Medical ethics has become more important in present days due to the advancement of biomedical technology. Today, medicine is not only for alleviating sickness and restoring health, but also to improve the quality of life. As pointed out by Charles E. Curran, the modern technologies create more ethical dilemmas compared to the past.[123]

The ethics of medicine according to Bernard Haring ‘represent[s] a systematic effort to illumine the ethos and to elaborate the perspectives and norms of the medical profession’.[124] He describes ethos as sharing traditions and customs among vocational groups rendering a service to the community.[125] Bioethics is defined as ‘a field of inquiry dealing with the moral obligations of health professionals and society in meeting the needs of the sick and injured, providing a framework for moral judgment and ethical decision making in the wake of phenomenal advancements in medicine’.[126]

Realizing the dangers that science can lead to; Potter suggests that bioethics is a new science of survival and it is a scientific methodology in testing ideas and developing them based on previous experience.[127] Bioethics is an interdisciplinary approach and not exclusive for the scientific approach. Bioethics is identified by Potter as a bridge between science and humanities that can take the present day into the future. The interdisciplinary nature of bioethics is well accepted as it includes the role of philosophers, biologists, physicians, theologians, psychologists, lawyers, health professionals and many others.[128]

[122] Curran, p. 59.
[123] Curran, p. 60.
[124] Haring, p. 25.
[125] Haring, p. 24.
[126] ‘Bioethics’, *Oxford Dictionary of Islam*, ed. by John L. Esposito (New York: Oxford University Press, 2003).
[127] For more details on the idea of Potter on bioethics, see Henk A. M. J. ten Have, 'Potter's Notion of Bioethics', *Kennedy Institute of Ethics Journal*, 22 (Mar 2012), 59-82.
[128] *Encyclopedia of Bioethics*, ed. by Warren T. Reich, Abortion to Extraordinary, (London: Free Press London, 1978); K. Danner Clouser, 'Bioethics', in *Encyclopedia of Bioethics*, ed. by Warren T. Reich (London: Free Press London, 1978), pp. 126.

However, Potter looks at bioethics as a philosophical notion that can lead to a progress in a society. He believes that religion is only a transcendental progress from this world to another world to come.[129] Against this view are religious bioethicists who believe that 'theology played a foundational role in its creation'.[130] In his research, David H. Smith lists the key figures among the earliest non-medical scholars who contributed to the discussions of medicine and ethics. He found out that, although there was a Jewish physician in his list, Christian and Jewish scholars were the key players in building up the discussion of medical ethics.[131] He argues that mainline philosophy was not a serious key subject at the beginning of the emergence of the discussion. He also argues,

> "The fact is that religiously informed thinkers were so influential at the beginning of the bioethics movement because a standpoint within a religious tradition helped them to say things that were true and insightful."[132]

This indicates that discussing about bioethics from a religious standpoint is not at all unusual. As Potter contends *bio* and *ethics* illustrate the combination of knowledge about science and humanity. Humanity and religion, on the other side, are corresponding and inseparable from each other.

Medical discourse has evolved from a discussion of illness, treatment and drugs to a more obscure scientific and technological advancement within the medical research. Initially, the traditional form of medicine was hypothetical to knowledge and belief in the pre-modern era. Adding 'bio' to the existing term of medicine indicates 'a step change in forms of knowledge and power.'[133] The term "biomedicine" has been coined to mark the transformation in the body of knowledge and associated clinical and

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[129] Henk A. M. J. ten Have, p. 64.

[130] Bonnie Steinbock, *The Oxford Handbook of Bioethics* (Oxford: Oxford University Press, 2007), p. 4.

[131] Among the scholars that have been pointed out in Smith's research are: i. Catholic philosophers: Daniel Callahan, 1930) and Hans Jonas (1903 – 1993); ii. Episcopal priest, Joseph Fletcher (1905 - 1991); iii. Protestants scholars: Helmut Thielicke (1908 – 1986), Karl Bath (1886 – 1968) and Dietrich Bonhoeffer (1906 – 1945); iv. Catholic theologians: H. Richard Niebuhr (1894 – 1962), Paul Ramsey (1913 – 1988), Bernard Häring (1913 – 1998), Richard McCormick (1947) and Charles Curran (1921 – 1980); and v. Jewish scholars: Fred Rosner, David Feldman, Immanuel Jakobovits (1921 – 1999) and David Bleich (1936).

[132] David H. Smith, 'Religion and the Roots of Bioethics Revival', in *Religion and Medical Ethics - Looking Back, Looking Forward*, ed. by Allen Verhey (Cambridge: William B. Eerdmans Publishing, 1996), 1, p. 15.

[133] Morgan Clarke and Thomas Eich, 'The Social Politics of Islamic Bioethics', *Die Welt Des Islam 55*, (2015), 265 – 277, p. 269.

experimental practices grounded in medical sciences.[134] It goes without saying that ethical issues become more complex and intricate with this sophisticated transformation that sparked the birth of 'bioethics'.

In Islamic worldview, medical ethics concerns with all aspects of medical practice. This includes professionalism, professional relations, health care professional character, conduct and accountability.[135] The transformation to biomedicine in the West also influenced the gestation of Islamic biomedical ethics in every part of the world through reflection on contemporary issues in medical practice and research.

2.3. In Search of Framework of Biomedical Ethics in Islamic Perspectives

As clearly stated in the title of this research, the medical condition of DSD will be studied through the evaluation of Islamic perspectives. It is required to define what is Islamic perspectives and how it should relate to the discussion on the rare conditions of gender ambiguity. Yet, Islamic perspectives on medical ethics show a vast array of discourses from various points of view. Therefore, a research has been done to explore the very subject of Islamic (bio)medical ethics in order to seek the most appropriate framework of this study. Most of literature deliberate its constituent and foundation on several facets, such as follow:

a. Religio-cultural approach and Muslim ethics.
b. Interplay between divine texts and context.
c. Application of discipline of principles of Islamic jurisprudence (*uṣūl al-fiqh*).
d. Aiming at achieving *maqāṣid al-sharīʿah* (the objectives of sharīʿah).
e. Fatwa and contemporary Islamic scholars' views.
f. Islamic ethics and pre-modern Islamic medical ethics.
g. Socio-political environment by the involvement of Islamic legal authority.
h. *Adāb* and morality.
i. Philosophical principles in Islamic perspectives.

[134] Muna Ali, 'The "Bio" in Biomedicine: Evolution, Assumptions, and Ethical Implications' in *Islamic Perpsectives on the Principles Biomedical Ethics,* ed. By Mohamad Ghaly (London: World Scientific Publishing (UK) Ltd., 2016) 1, 41 – 68, p. 44.

[135] Jamal Jarallah, 'Islamic Medical Ethics: How Different?', *Journal of Taibah University Medical Sciences,* 3 (2008), 61 – 63, p. 61.

In fact, these facets are closely interrelated to each other. The researcher discovered that Islamic biomedical ethics is not merely an attribution to ethics and morality. Beyond its name, this discipline is much more directed towards the connection between its foundation, scopes of discussions and actors that contribute to its formation. Hence, those identified facets are grouped into three typologies, which are foundation, scopes and actors as presented in Figure 2.

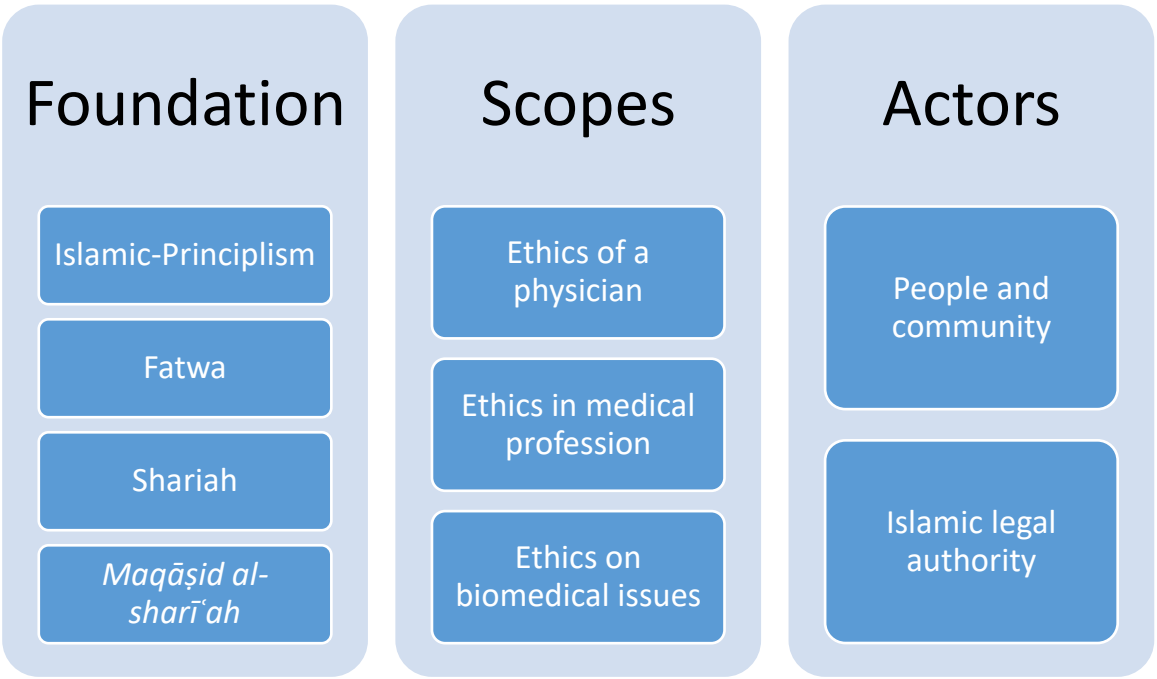

Figure 2: Typology of Discourse on Islamic Biomedical Ethics

2.3.1. Foundation of Islamic Biomedical Ethics

The first type of exploration in Islamic biomedical discourse is upon its foundation. Muḥammad ʿAlī al-Barr and Zuhayr Aḥmad al-Sibāʿī mention, "medical ethics should be based on constitution that defines its features and enduring rules upon which its construction anchors. The constitution refers to the Qurʾān and Prophetic Sunnah."[136] Yet, there are different views on how these sources are referenced to in understanding the whole concept of Islamic biomedical ethics. The researcher divided these opinions into four groups, namely, Islamic-*Principlism*, fatwa-based, *Maqāṣid*-based approach and Islamic-juridical-ethical approach.

[136] Zuhayr Aḥmad al-Sibāʿī and Muḥammad ʿAli al-Barr, *al-Ṭabīb Adabuh wa Fiqhuh (Ethics of Physician and Its Jurisprudence),* (Damascus: Dār al-Qalam, 1993), p. 10.

2.3.1.1. Islamic-*Principlism*

There are a number of philosophical theories on medical ethics. One of which is widely debated is a theory proposed by Tom Beauchamp and James Childress through their 7-edition book, entitled, *Principles of Biomedical Ethics*. Beauchamp and Childress stand for a set of principles that is deemed to be a universal moral and ethical codes, which are respect for autonomy, beneficence, nonmaleficence and justice. These principles were also known as *Principlism* as coined by K. Danner Clouser and Bernard Gert in their response, *A Critique of Principlism.*[137]

Beauchamp and Childress argue that the principles – respect for autonomy, justice, beneficence and non-maleficence – are constructed from common morality which comprises full set of universal norms, hence universal principles. Though, "this framework is abstract and thin in content until it has been further specified."[138] Specification is a process of adding action-guiding content to general principles. These principles will work well in various conditions and cultural backgrounds, according to them, including fulfilling religious requirements.

One of the examples is presented through their response to some critiques - pertaining to this *Principlism* – made by Professor Ali Qaradaghi on consent of medical intervention.[139] Professor Qaradaghi said that, "the patient's permission of the treatment is essential if the patient is in full legal capacity to give it. If he is not, the permission of his (her) legal guardian shall be sought according to the order of guardianship *in sharia*."[140] Beauchamp and Childress assert that the '*in sharia*' is a kind of specification towards 'permission' which is universally observed in biomedical ethics. The specification or additional action required is on selection of guardianship based on Islamic law.

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[137] K. Danner Clouser and Bernard Gert, 'A Critique of Principlism', *the Journal of Medicine and Philosophy*, 15 (2) (1990), 219 – 236.

[138] Tom L. Beauchamp, 'The Principles of Biomedical Ethics as Universal Principles' in *Islamic Perspectives on the Principles Biomedical Ethics,* ed. by Mohamad Ghaly (London: World Scientific Publishing (UK) Ltd., 2016) 2, 91 – 120, p. 94.

[139] Professor Ali Qaradaghi is a Secretary General of International Union of Muslim Scholars and also serves as member of Shariah Advisory Board for several banks in Muslim world.

[140] Tom L. Beauchamp, 'The Principles of Biomedical Ethics as Universal Principles', 2016, p. 44.

In order to draw similar standard with what is expected to be globally and universally accepted principles of biomedical ethics, some scholars put significant efforts to specify – to use Beauchamp and Childress' word – or even to adapt the principles within the Islamic dogma. Gamal Serour, Muḥammad ʿAlī al-Barr, Hassan Chamsi-Pasha, Aksoy Sahin and Ali Tenik are among scholars who contribute to this perspective. Grounding their deliberation, all of them begin the explanation with first understanding the sources of Islamic law, namely the Qurʾān and Ḥadīth as well as other juridical tools for prescribing Islamic rulings. The four principles are then elaborated by indicating the Quranic verdicts or Ḥadīth that are related to them.

Among the four principles, autonomy is viewed as the most controversial principle within the Islamic purview. Gamal Serour is a Professor of Obstetrics and Gynaecology, Director of International Islamic Centre for Population Studies and Research at al-Azhar University. He holds onto the four-principles but states that if autonomy of a person contradicts with public interest, the latter is given priority.[141] Muḥammad ʿAlī al-Barr, a Director of Medical Ethics Centre, International Medical Centre, Jeddah, and Hassan Chamsi-Pasha, a Consultant Cardiologist and Head of Non-Invasive Cardiology at King Fahd Armed Forces Hospital in Jeddah, produce a book on *Contemporary Bioethics: Islamic Perspectives*. Each principle, as proposed by Beauchamp and Childress, is explained in a separate topic. They assert that autonomy in Islam is not absolute because human can only act in the way already prescribed by God.[142]

Sahin Aksoy, a researcher at Harran University, Turkey published an article on the four principles of bioethics. This article is co-authored with his colleague, Ali Tenik from the same university. Aksoy and Tenik justify the applicability of these principles through Mawlana Jalaladdin Rumi's thoughts way back in the 13th century.[143] Rumi (d. 1253) was a well-known theologian and Sufi. He concentrated mostly on God's

[141] Khalid al-Ali, Gamal Serour and Alireza Bagheri, 'Challenges in Islamic Bioethics' in *Islamic Bioethics: Current Issues and Challenges,* ed. By Alireza Bagheri and Khalid Abdulla al-Ali, (London: World Scientific Publishing Ltd., 2018), p. 234.

[142] Muḥammad ʿAli al-Barr and Hassan Chamsi-Pasha, *Contemporary Bioethics-Islamic Perspectives* (Springer, Cham, 2015), https://doi.org/10.1007/978-3-319-18428-9, p. 115.

[143] Sahin Aksoy and Ali Tenik, 'The 'Four Principles of Bioethics' as Found in 13th Century Muslim Scholar Mawlana's Teachings', *BMC Medical Ethics*, 3 (2002), http://wwwbiomedcentral.com/1472-6939/3/4.

command and explored the ‘inner power’ of man. As unanimously argued, according to him, Islam does not permit absolute autonomy but limits with certain rules. Man is a representative of God and God reflects His attributes only on man. Therefore, autonomous decision with the ‘share’ of God in it shall be respected if it is carried out with *ʿilm* (knowledge).

However, Mohamad Ghaly, a Professor of Islam and Biomedical Ethics at research Centre for Islamic Legislation and Ethics (CILE), Qatar, considers these views as instrumentalist approach. It is because Quranic verses and Ḥadīth are quoted and presented as instruments to justify the compatibility of *Principlism* within Islamic underpinnings. He argues that “the Islamic tradition is not approached as a source of knowledge but as possible justifier for already existing assumptions embraced by principle-based bioethics.”[144] A more concrete and foundational framework of Islamic bioethics is crucial to ensure its sustainability across times and geography, as the sources of Islamic law themselves are persistence and harmonious with different cultures and societies.

2.3.1.2. Fatwa-based approach

Fatwas are always recognised as a point of departure when discussing Islamic perspectives pertaining to biomedical issues. It is a legal response provided by mufti (authoritative jurist) or certain religious scholars, upon request from an interlocutor (*mustaftī*). Referring to fatwa is an effortless and a straightforward action in order to comprehend Islamic stands on certain issues. Fatwa helps individuals and communities to understand contemporary biomedical issues by considering local environment, cultural and necessitates. Unsurprisingly, diverse legal opinions exist as it may differ due to the local context, despite the differences on Islamic schools of thoughts and their principles that the jurists hold on to.

Vardit Rispler-Chaim, a lecturer at University of Haifa, Israel, analyses Islamic biomedical ethics based on Egyptian fatwas. She summarizes the main characteristics of Islamic medical ethics, based on her study, which are:

[144] Mohammed Ghaly, ‘Introduction’ in *Islamic Perspectives on the Principles Biomedical Ethics,* ed. by Mohamad Ghaly (London: World Scientific Publishing (UK) Ltd., 2016), p. 4.

a. There is a constant attempt to base modern medical treatments in the classical sources of Islamic law.
b. The problems raised are pertinent predominantly to Muslims or derive directly from the commandments and prohibitions of Islamic law.
c. When Islamic law and the state law on certain medical ethics are contradictory the fatwa is issued to mediate.
d. Islamic medical ethics tend to be apologetic or to show the superiority of the Islamic way of life over that of other societies, especially in the West.
e. Islamic medical ethics are often inseparable from social and political issues.[145]

It is not the objective of this subtopic to discuss thoroughly each point that Rispler-Chaim made. It is sufficient however to note that fatwa is human interpretation of the Lawgiver's texts at the best manner that the jurists could make based on the discipline of Islamic jurisprudence. Fatwa is studied in both, vertical and horizontal directions. Vertically, fatwa is examined to explore the jurisprudential mechanisms employed by the scholars including identifying proof of injunctions, Quranic and Ḥadīth texts and up to which the objectives of sharīʿah are to be achieved. This provides foundational discourse of Islamic biomedical ethics. In addition, fatwa is also examined horizontally by defining the character of related parties including the mufti, societies and governmental authorities. At this juncture, fatwa is then recognised as a product of interaction between Divine revelations, legal interpretation and ethnographical consideration. Thus, the roles played by the jurists and their attitudes are continuously studied as will be described further in the third typology of Islamic bioethical discourse.

Biomedical issues are frequently explored through available fatwas found around the globe. Technology increases the possibility of seeking various juristic opinions across geographical boundaries as most prominent individual jurists and institutional jurist councils have their own webpage for public access. Comparison and integration are made between them due to the limitation of fatwa's nature that focuses on answering the question, rather than issuing an elongated explication on certain issue. The

[145] Vardit Rispler-Chaim, 'Islamic Medical Ethics in the 20th Century', *Journal of Medical Ethics*, 15 (1989), 203-208, p. 203.

researcher is of the opinion that the analysis of biomedical issues is more viable if the fatwas are examined thoroughly by understanding their jurisprudential mechanisms. This will enlighten the readers on the very basic framework of Islamic bioethics and its elasticity due to several factors such as the changing cause of rulings, utilization of different proof of injunctions and varied customary practices.

2.3.1.3. Islamic Juridical-Ethical Approach

Currently, Muslim scholars increasingly turn to underlying principles of sharīʿah in search of durable guiding principles of Islamic biomedical ethics. Sharīʿah refers to the God's eternal and immutable will for humanity and is known as ideal Islamic law.[146] The God of universe sends down His decree through two Divine scriptures, i.e. the Qurʾān and Ḥadīth for all mankind. The Qurʾān is regarded as the *ipsissima verba,* the revelation of Allah sent upon the Prophet Muḥammad through the angel Jibraʾil. It is the most authentic source as promised by Allah and its status of authenticity is regarded as definitive state (*qatʿi al-thubūt*) due to its verbal perpetuation (*tawātur*).[147] Meanwhile, Ḥadīth refers to what is narrated from the Messenger's saying, action, approval or characteristics. It is regarded as the second source after the Qurʾān since it is categorised as speculative proof (*ẓanni al-thubūt*) except those *Aḥādīth* which are recognised as Ḥadīth *mutawātir*. These Divine revelations of the only God comprise of universal commandments that uphold universal moral characters and virtues. Thus, it is a significant effort to expound the epistemology of ethics in Islam and revive the classical notion of *maqāṣid al-sharīʿah* (the objectives of sharīʿah, which will be described later) through its juridical tool of the principles of Islamic jurisprudence (*ʾuṣūl al-fiqh*).

Abdulaziz Sachedina, a Professor and International Institute of Islamic Thought Chair in Islamic Studies at George Mason University in Fairfax, Virginia, says that, "since biomedical issues occur both in the area of interhuman as well as human-divine

[146] *Oxford Dictionary of Islam,* ed. by John L. Esposito ([New York]; [Oxford]: Oxford University Press, 2003).

[147] Allah granted in His Holy Book that "We have, without doubt, sent down the Message (the Qurʾān); and we will assuredly guard it (from corruption)." Translation from *Sūrah Ibrāhīm*, 15: 9.

relations, Islamic juridical inquiries tend to be comprehensive."[148] He mentions that universalization of secular bioethics that has been proposed in medical education has led to erroneous assumptions among healthcare professionals and Muslim societies due to its limited applicability that does not fully resonate with the local and regional Muslim values.[149]

Thus, the quest for principles of bioethics in Islamic legal-ethical tradition is vital to ensure the realization of the objectives of sharīʿah and its compatibility with Muslims' experiences. The result of this enquiry will render a robust and yet malleable foundation to serve multi-cultural and multi-races background of Muslim communities around the world. Proper examination of the underlying principles and rules of practical ethical guidance in the Islamic tradition will surpass the numerous research that were made merely by passing references to the Qurʾān and Ḥadīth as a justifier to the available concept of biomedical ethics.

Unlike philosophical or secular ethics, according to Aasim Padela, ethical codes in Islam begin with faith in Allah and other pillars of Islam, followed by morality for individuals and society to approach Him as far as possible.[150] Padela argues that sharīʿah is the way to approach Him through state law and personal life, collectively and individually respectively. Subsequently, any discussion of Islamic medical ethics should include analysis of the sharīʿah. It is interesting to note that the birth of this new discipline of Islamic bioethics provides a means for Islamic ethico-legal traditions to be applied in response to social changes in health and medicine, new biomedical technologies, and understandings of human biology that challenge previously held assumptions.[151]

Sharīʿah as understood by the Muslims is derived from divine scriptures, namely the Qurʾān and Ḥadīth. Both are viable sources of Islamic law, despite the debate of the authoritativeness of the latter source on its variants. Mohamad Ghaly describes these

[148] Abdulaziz Abdulhussein Sachedina, *Islamic Biomedical Ethics Principles and Application*, (Oxford; New York: Oxford University Press, 2009), p. 8.

[149] Abdulaziz Abdulhussein Sachedina, p. 8.

[150] Aasim I. Padela, 'Country Report: Islamic Ethics: A Premier', *Bioethics*, 21 (2007), 169-178, p. 174.

[151] Aasim I. Padela, Hasan Shanawani and Ahsan Arozullah, 'Medical Experts and Islamic Scholars Deliberating over Brain Death: Gaps in the Applied Islamic Bioethics Discourse', *The Muslim World (Hartford)*, 101 (1) (2011) 53 – 72, p. 54.

sources as being able to manifest one of the textual elements that play a greater role in their interplay with context especially throughout the discussion of Islamic biomedical ethics.

Any legal rulings or *aḥkām* (sing. *ḥukm*) in Islam has to be based primarily on the Qurʾān, Ḥadīth and ʾ*ijmāʿ* (consensus of Muslim scholars). In the absence particular reference of narrations from those three sources, *ijtihād* will be conducted. *Ijtihād* literally means exertion. Technically it refers to the effort of a jurist makes in order to deduce the law, which is not self-evident, from its sources and it is a legal independent reasoning.[152] Here, the discipline of principles of Islamic jurisprudence (ʾ*uṣūl al-fiqh*) is applied to deduce the practical legal rulings from the detailed foundational sources.

The *ijtihād* process is concerned with hermeneutic and deductive principles through which several mechanisms are employed including *al-qiyās* (analogical reasoning), *al-raʾy* (sound opinion), *al-istiṣlāḥ* (promoting the good), *al-istiḥsān* (selecting the most beneficial), ʿ*urf* (customs) and *sadd al-zarāʾiʿ* (blocking means). These tools and their specific technique of analysis are known as *qawāʿid* ʾ*uṣūliyyah* (principle methodologies). Subsequently, Islamic legal maxims enrich these mechanisms of Islamic law, hence making it more flexible and elastic. These tools, which are utilised by a mufti or a jurist to provide fatwas or religious decrees, help scholars in discerning the contemporary biomedical issues from its ethico-legal perspective.

2.3.1.4. Maqāṣid-based Approach

Disentangling new emerging issues based on the available fatwas, as a result of *ijtihād,* sometimes does not seem to feed the purpose of sharīʿah. In addition, it is also observed that the failure of tool of *qiyās* has led many contemporary scholars to turn to the basic of sharīʿah on its underlying objectives or known as *maqāṣid al-sharīʿah* to derive robust and consistent rulings.[153] Ghaly, Al-Barr, Chamsi-Pasha, Padela, Omar Kasule, Ghaiath Hussein and Jasser Auda are among many other Islamic

[152] Mohammad Hashim Kamali, *Principles of Islamic Jurisprudence*, Revised edn (Cambridge: The Islamic Text Society, 1991), p. 366.

[153] Omar Kasule, 'Biomedical Ethics: An Islamic Formulation', *JIMA* 42 (2010), 38-40, p. 38.

scholars, physicians and bioethicists that propose this current paradigm in analysing Islamic biomedical ethics.[154]

Maqṣid (plural: *maqāṣid*) refers to a purpose, intent, objective or goal. The term *maqāṣid al-sharīʿah* refers to the purposes/intents/objectives/goals behind the Islamic rulings. *Maqāṣid* is also used interchangeably with *maṣāliḥ* (people's interests; sing. *maṣlaḥah*) or *maṣāliḥ al-ʿāmmah* (publid interests).[155] Al-Ghazālī, (d. 505 AH/1111 CE), a prominent jurist in Shāfiʿī school of thought, who placed this discussion under the topic of 'unrestricted interests' (*maṣāliḥ al-mursalah*), clarifies that the objectives of sharīʿah is to attain well-being of all mankind. The attainment is through safeguarding five basic elements including i) faith, ii) life, iii) mind, iv) offspring and v) wealth.[156] The act of preservation encompasses two sides which are safeguarding these elements and protecting them from any destruction. The extent of which these five elements should be preserved are divided into three levels of *maqāṣid* based on its strength namely, the essentials or necessities (*al-ḍarūriyyāt*), the complimentary (*al-ḥājiyyāt*) and the embellishments (*al-taḥsīnyyāt*). Al-Ghazālī emphasizes that the act of preservation should be done mainly when it comes to the level of necessities, it is the highest level, more important than the levels of complimentary and embellishments.[157]

Some scholars interpreted the five elements as the objectives of sharīʿah themselves. Kasule elaborates the five elements as the general purposes of sharīʿah that should be protected, preserved and promoted. With clear and robust purposes, all ethical issues can be resolved, and thus other laws are undesirable.[158] The preservation of these five elements includes, firstly the protection of *imān* (faith) as well as other religious obligatory duties (*ʿibādah*). Therefore, promoting good health and providing

[154] Muḥammad ʿAli al-Barr and Hassan Chamsi-Pasha, p. 48; Jasser Auda, 'A Maqāṣid-Based Approach: A New Independent Legal Reasoning (*Ijtihād*) in in *Islamic Perspectives on the Principles Biomedical Ethics,* ed. By Mohamad Ghaly (London: World Scientific Publishing (UK) Ltd., 2016) 1, 69-88, p. 69; A. R. Gatrad and A. Sheikh, 'Medical Ethics and Islam: Principles and Practice', *Archives Disease in Childhood*, 84 (2001) 72 – 75, p. 74; Omar Kasule, *The Legal and Ethical Basis of Medical Practice*, Workshop on Use of Ijtihad Maqasidi for Contemporary Ethico-Legal Problems in Medicine, Fiqh Academy of India, Hyderabad, 3 – 4 February 2007

[155] Jasser Auda, *Maqasid al-Shariah An Introductory Guide,* (Herndon VA: IIT, 2008), p. 6.

[156] Muḥammad Muḥammad Al-Ghazālī, *Al-Mustaṣfā fī ʿIlm Al-Uṣūl (the Seeking of Purity in the Science of Jurisprudence's Principles)*, ed. by ʿAbd al-Salām ʿAbd al-Shāfī, vol. 2 (Beirut: Dār al-Kutub al-ʿIlmiyyah, 2000), p. 482.

[157] Abū Ḥāmid Muḥammad ibn Muḥammad al-Ghazālī, p. 481.

[158] Omar Kasule, 'Biomedical Ethics: An Islamic Formulation', p.39.

medical assistance is also a form of preserving the faith as it will permit people to practise and perform their religious duties properly.

Secondly, in order to practice the Islamic teaching, maintaining a good life is crucially needed. Medical engagement is necessary if the one's health is at risk.[159] In this case, medicine is seen as contributing to the protection and continuation of life, the prevention of disease and the treatment and rehabilitation of ailment.[160] Thirdly, the protection of mind is attainable by preventing and treating neuroses, psychoses, personality disorders and other various addictive disorders. The deterioration of the mental faculty either caused by alcohol or drug abuse, physical illness or a stressful way of life should be treated to protect the human mind. Again, medicine plays its role to achieve this purpose.

The next element is the protection of offspring. Undoubtedly, the creation of humans as mentioned in the Qurʾān is for the continuation of generations.[161] For the purpose of maintaining a sustainable population growth, current biomedical technology contributes to rectifying infertility and providing prenatal and paediatric care to ensure that a young generation is born and grows healthy.[162] The last element is regarding the protection of resources. It involves wealth acquisition, ownership and the circulation of money for building up a socially and economically stable society. However, it is unachievable if the community is facing general poor health, thus becoming less productive and less vibrant society. The special application in medical practice is through avoiding waste of resources, conserving energy and protecting the environment in the hospitals.[163]

Ghaiath Hussein, a bioethicist, is among a few scholars who enumerates the definition of Islamic bioethics. He emphasizes the objectives of sharīʿah when he describes Islamic bioethics as 'a methodology of defining, analysing and resolving ethical issues that arise in health care practices or research based on Islamic moral and legislative

[159] Abul Fadl Mohsin Ebrahim, 'Method and Sources of Justification of Islamic Medical Ethics', *4th International Islamic Bioethics Conference*, Coimbra, Portugal, 5 August 2015.

[160] Omar Kasule, *The Legal and Ethical Basis of Medical Practice,* Workshop on Use of Ijtihad Maqasidi for Contemporary Ethico-Legal Problems in Medicine, Fiqh Academy of India, Hyderabad, 3 – 4 February 2007.

[161] The Qurʾān, *Sūrah al-Nisāʾ* (The Women), 3: 1

[162] Omar Kasule, *The Legal and Ethical Basis of Medical Practice,* p. 6.

[163] Omar Kasule, 'Biomedical Ethics: An Islamic Formulation', p.39.

sources (the Qurʾān, Ḥadīth and *ijtihād*) aimed at achieving the goals of sharīʿah Islamic morality (i.e. preservation of the human religion, life, mind, wealth and progeny)'.[164] This definition is not clearly understood from the literal meaning of the terminology. Rather, it provides an operational definition involving key aspects of sharīʿah law and denoting the dynamic progress of interpreting classical views on *maqāṣid al-sharīʿah* in contemporary issues.

While most literature mention the necessity to consider *maqāṣid al-sharīʿah,* Auda goes far beyond merely referring to its five principles of preservations. Modern scholarships propose that the classical hierarchy of higher objectives could be widened into other classifications such as classification based on: [165]

a. Scope of rulings - the scope is divided into three, i.e., general higher objective, specific higher objective and partial higher objective.
b. Scope of people - from individual sphere to the nation interests.
c. Level of universality – directly induced the scripts rather than from the body of fiqh (Islamic law).

Auda mentions that these multi-dimension structures are all valid dimensions that represent valid viewpoints and classifications. Hence, if there are opposing evidences occur in one particular case, these multi-dimensional structures will offer better ways to reconcile the evidences by taking into account a higher objective between them. The same method applied in understanding or interpreting the evidences in a unified context based on the purpose of both evidences.[166] The second proposal on higher objective based approach, made by Auda is to differentiate between changing means and absolute ends. In Divine revelations, there are traditions that required clear understanding of to which stage the commandments are referring to, either as means or as ends in their own right.[167] This differentiation, as well as the multi-dimension method, will ensure the flexibility of the rulings with the change of time and circumstance.

[164] *Professionalism and Ethics Handbook for Residents (PEHR): A Practical Guide*, ed. by James Ware, 1st edn, ed. by Ghaiath MA Hussein, Abdulaziz Fahad Alkaaba and Omar Hassan Kasule (Riyadh: Saudi Commission of Health Specialties, 2015), p. 7.
[165] Jasser Auda, 'A Maqāṣid-Based Approach: A New Independent Legal Reasoning (*Ijtihād*), p. 73.
[166] Jasser Auda, 'A Maqāṣid-Based Approach: A New Independent Legal Reasoning (*Ijtihād*), p. 84.
[167] Jasser Auda, 'A Maqāṣid-Based Approach: A New Independent Legal Reasoning (*Ijtihād*), p. 79.

2.3.2. Scopes of Islamic Biomedical Ethics

Based on the scope of discussion, ethics in medical setting can be broadly grouped into three areas, namely:

- Ethics of a physician
- Ethics on medical profession
- Ethics on biomedical issues

2.3.2.1. Ethics of a Physician

Since its inception, ethics is widely discussed related to the conduct of a physician as an individual as well as a profession. In Islam, the ethics of a person comprises both inner and outer self, which grow from one's religious belief and faith, then translated into actions towards him/herself and the people around them especially patients, their family and society. As early as in the 4th century of Hijri when Al-Ruhāwī, a prominent physician, mentions the process of nurturing with goods ethics (*al-taʾdīb*) will transform a person from animal dispositions to human ethics especially when it is firmly established in humanity through the customs of the society.[168] He uses the word *al-taʾdīb* in his book *Adab al-Ṭabīb* (the Ethics of Physicians), which is derived from the word *adab* to signify morality.

Al-Ruhāwī begins his writing with clear emphasis on spirituality and beliefs. He says there are three articles of faith that a physician should hold on to. Firstly, for all creations and beings, there is one Creator who is the All-Wise and All-Powerful in doing things according to His will. Secondly, a physician must believe in the great Allah with a firm affection, and devote himself towards Allah with all his reason, soul and free will. Thirdly, a physician must also have faith that Allah sent down His Messengers to teach what is good, in which mind alone is insufficient to contemplate what is beneficial for them without the guidance from the Messengers.[169] Al-Ruhāwī also points out good conducts of a physician towards himself, i.e., towards his soul and body is more valuable compared to wealth.[170] Hence, one should look after himself

[168] Isḥāq ibn ʿAlī Al-Ruhāwī, *Adab Al-Ṭabīb (the Ethics of Physician)*, ed. by Murayzin Saʿīd Murayzin ʿĀsīrī, 1st edn (Riyadh: Markaz al-Malik al-Fayṣal li al-Buḥūth al-Dirāsāt al-Islāmiyyah, 1992), p. 63.
[169] Isḥāq ibn ʿAlī Al-Ruhāwī, p. 41.
[170] Isḥāq ibn ʿAlī Al-Ruhāwī, p. 40.

spiritually, physically and ethically. He also pinpoints that a physician should possess good ethical conduct and act decently towards others including healthy people, patients and visitors.

His exploration can be seen as an extension of what was said by Muḥammad Ibn Zakariyā al-Rāzī (d. 313AH/ 925CE) on spiritual medicine. Al-Rāzī emphasizes the importance of mind as the exclusive way to differentiate between human and animals, in which its ability will work upon proofs and evidence to cure wickedness of spirituality.[171] Being informed by this foundation of ethics and manners, classical literature on Islam and ethics focuses more on the characteristics of the physicians and their relationship with God, themselves, patients, society and their profession. The Hellenistic approach to medical ethics was believed to be incorporated within al-Ruhāwī and al-Rāzī's writing although some elements disagree.

Another word related to *adab* is ***akhlāq. Akhlāq,*** which is derived from the word *khalaqa* (literally means 'to create'), refers to a set of individual dispositions and human actions whether good and bad. It is innate and comprises of the internal dispositions of a person. *Akhlāq* is illustrated in a person's appearance in term of its meaning and characteristics.[172] It includes any pre-Islamic ethics which were in concord with Islam whether practised or otherwise to achieve the purpose of seeking Allah's pleasure.[173]

2.3.2.2. Ethics in Medical Profession

Individual ethics is a feature of professionalism in health care services and research, which encompass several other branches in bioethics such as clinical ethics, research ethics, resource allocation ethics, public health ethics, nursing ethics and others.[174] Ibn Qayyim (d. 751 AH/1350 CE) had long ago emphasized that every doctor should take responsibility on their career and to ensure that they are holding good qualifications including acquiring 'knowledge, balance, confidence, patience,

[171] Muḥammad ibn Zakariyā Al-Rāzī, *Al-Ṭibb Al-Rūḥānī*, ed. by Abd al-Laṭif Al-ʿAbd (Cairo: Maktabah al-Tuḥfah al-Bashariyyah, 1978), p. 48.

[172] Muḥammad Ibn Mukarram Ibn Manẓūr, *Lisān al-ʿArab*, 3rd edn, vol. 8, (Beirut: Dār Ṣādir, 1414H), p. 86.

[173] Al-Zayd, ʿAbd al-Raḥman ʿAbd al-Karīm, *Waqafāt Maʿ Aḥādīth Tarbiyyah Al-Nabiy Ṣalla Allah ʿAlayh Wa Sallam Li Ṣaḥābatih (Standpoints with Educational Traditions of the Prophet (Pbuh) for His Companions)* (Medina: Al-Jāmiʿah al-Islāmiyyah bi al-Madīnah al-Munawwarah, 1424H), p. 122.

[174] *Professionalism and Ethics Handbook for Residents (PEHR): A Practical Guide*, p. 6.

forbearance, fear of wrongdoing, and similar professional characteristics, besides mastering the use of the tools of the profession.'[175]

On the other hand, contemporary scholars like Hassan Hathout, Muḥammad ʿAlī al-Barr and Zuhayr Aḥmad al-Sibāʿī emphasize on the awareness of Islamic rulings on both rights and obligations of doctors and patients during and post medical intervention. Hassan Hathout, a co-founder of International Organisation of Medical Sciences (IOMS), explains, a physician's deontology includes possession of threshold of knowledge, worship and essentials of Islamic jurisprudence (*fiqh*). In doing so, according to him, the doctor may advice and counsel to Muslim patients when they are seeking his guidance about health, treatment and bodily conditions in line with sharīʿah teachings.[176] Patients may ask more than only ailment and treatments. When certain medical interventions recommended by the doctors are further questioned, for example; how can I perform my religious duties undergoing procedures? Or will it affect performance of prayer, fasting, pilgrimage? It is expected for Muslim doctors to have good basic knowledge of *fiqh* so it will help the patients in getting a better quality of life as a dutiful Muslim.

Muḥammad ʿAlī al-Barr is a medical consultant in King Fahd Centre for Medical Research, Saudi Arabia. Al-Barr's book, *Al-Ṭabīb Adabuh Wa Fiqhuh (Ethics of Physician and its Jurisprudence)*', which is co-authored with Zuhayr Aḥmad al-Sibāʿī, presents similar context in greater details. It is divided into two chapters. The first chapter, which is originally an article written by al-Sibāʿī, entitled '*Characteristics of Muslim Physician'*, deliberates on ethics and morality in medical profession. He describes ten main characteristics, which are belief in the honour of the profession, self-discipline, knowledge empowerment, scientific methodology of thinking, socialization, affection, truth-telling, justice, humbleness and God-conscious.[177] These characteristics are expected in dealing with patients and society at large.

[175] Shamsuddin Muḥammad ibn Abī Bakr ibn Qayyim al-Jawziyyah, *Al-Ṭibb Al-Nabawī (The Prophetic Medicine)*, ed. by ʿAbd al-Ghinā ʿAbd al-Khāliq, ʿAdil al-Azharī, Maḥmūd Farraj al-ʿUqdah (Beirut: Dār al-Fikr, n.d.), p. 110.

[176] Hassan Hathout, 'The Medical Profession - an Islamic Perspective', *Journal of Islamic Medical Association of North America*, 20 (1988), 25 – 32, p. 26.

[177] Zuhayr Aḥmad al-Sibāʿī and Muḥammad ʿAli al-Barr, pp. 38-74.

Al-Barr also underscores the importance of possessing knowledge in religio-medical jurisprudence on the states of health and illness, providing guidance for patients and nurturing them with medical information and Islamic rulings. The knowledge comprises of three folds, which are:

a. Islamic rulings related to act of worships such as hygiene, prayer and fasting.
b. Islamic rulings related to transaction pertaining to medical profession.
c. Studies on modern applied medical conducts in the light of Islamic perspectives.

While moral and ethical conducts should be observed during carrying out the duty as a doctor, the liability may or may not arise, according to Ibn Qayyim, based on the circumstance below:[178]

a. A qualified doctor who performs his duties according to sharīʿah's principles will not be liable.
b. An unqualified doctor who performs his tasks and cause injury but at the same time, his lacking expertise is known by the patients, will not be liable.
c. A qualified doctor who mistakenly cause injury to uninjured parts of the patient's body will be liable on his mistakes.
d. A qualified doctor who develops new treatment but causes injury or death, there are two opinions, either compensation will be paid to the patients by the government (*bayt al-māl*) or the doctor will be liable.
e. A qualified doctor who performs his duties without the consent of the patients or the guardians and causes injury will be liable for the negligence.

2.3.2.3. Ethics on Biomedical Issues

Recent biomedical technology advances have resulted in a proliferation of complex issues and thus increasing ethical dilemmas for healthcare providers, patients, their families and societies. This can be seen in several literature that shift the focus from moral virtue in medical profession towards engagement in healthcare services in its sense. It sparks huge scholarly debates in resolving disputes over a number of

[178] Shamsuddin Muḥammad ibn Abī Bakr ibn Qayyim al-Jawziyyah, pp. 110-111.

biomedical issues such as organ donation, abortion, milk bank, vaccination, euthanasia and others, let alone matters that would arise relation to Islamic rulings. Hathout encourages physicians to equip themselves with contemporary and updated knowledge on modern biomedical advances. Abul Fadl Mohsin Ebrahim, a scholar of Islamic Bioethics and an Emeritus Professor of Islamic Studies at University of KwaZulu-Natal, South Africa echoes Hathout's reminder for Muslim doctors to combine within himself scientific acumen and high moral qualities. Moral characters and ethics as prescribed by scholars as an individual or when in professional arena are expected to be applied in resolving current ethical dilemmas.

On this occasion, Aasim Padela, an Associate Professor of Medicine at University of Chicago, describes that bioethics concerns with the moral and philosophical implications of biomedicine. Therefore, religious understanding and interpretations are important for patients and providers as resources of defining, articulating, and evaluating the moral, philosophical and ethical issues pertaining to biomedicine.[179] Religious understanding is not limited to the ethical clinical conduct, but it may include diverse aspects on Islamic legal rulings. For example, scholars speak about marriage contracts in Islam in resolving dilemma related to assisted reproductive technologies such as in vitro fertilization and surrogate motherhood.[180] Similarly, Islamic stands on life and death is examined in response to several biomedical issues including euthanasia, abortion and organ transplantation from cadaveric donors. The condition of *khunūthah* is also examined in resolving issues over gender ambiguity and sex reassignment surgery.[181] This latter example will be further analysed in this particular research.

The central issue is on the conformity of Islamic legal rulings while benefitting modern biomedical technologies for sustainable quality of life and public interests. Islamic legal rulings are not merely on permissibility or impermissibility. It implies ethical responsibilities towards oneself and communities. For instance, marital contract is

[179] Aasim I. Padela, 'Islamic Bioethics: Between Sacred Law, Lived Experiences and State Authority', *Theoretical Medicine and Bioethics: Philosophy Medical Research and Practice,* 34 (2013), 65-80, p. 65.

[180] Abul Fadl Mohsin Ebrahim, *Biomedical Issues – Islamic Perspective* (Mobeni: Islamic Medical Association of South Africa, 1988), pp. 109-116.

[181] Abdulaziz Abdulhussein Sachedina, *Islamic Biomedical Ethics Principles and Application,* (Oxford; New York: Oxford University Press, 2009).

highly observed in order to preserve dignity of a person and familial institution towards building up a strong and harmonious communal socialization. However, matters arise in observing its conformity amidst contradictory fatwas in particular cases, especially those of contemporary issues (*qaḍāyā muʿāṣirah*) which are found to be silent in Divine scriptures and are left for scholars' legal discretion (*ijtihād*). Let's take the long-debated issue on organ donation as an example. A number of fatwas have been issued since 1925 with plurality opinions as have been shown in Mansur Ali and Usman Maravia's study. Based on their extensive reading on numbers of fatwas there are seven Islamic positions on organ donation that found their ground explication in Islamic sources of law. Therefore, people are at liberty to choose any position without religious or moral fault [182]

2.3.3. Actors

Undoubtedly, ethics is about human matters on how one ethically acts towards another. Human are recognised as the 'moral agent' who have the ability to choose among alternatives to do or not to do things ethically based on certain ethical belief that one holds on to. Bioethics is then referred to as a 'moral reference' to justify any action that will be or has been carried out by the actors.[183] The differences of knowledge background, beliefs, cultures and expertise among the actors shape a range of implications within such society. Therefore, the study of social interaction and the roles of involved parties are important as they contribute towards the essence of biomedical ethics. Ghaly describes this as an interplay between text and context when he illustrates Islamic bioethics as a coin. The first side is text, encompasses Divine scriptures (the Qurʾān and Ḥadīth) and texts produced by humans (fatwas or ethico-legal advices). The other side is context of understanding the reality of people (*Aḥwāl al-nās*). Dealing with the texts is inseparable with the context within which the rulings derived from the scriptures and fatwas address human beings in general, who differ enormously from each other due to different context they live in.[184]

[182] Mansur Ali and Usman Maravia, 'Seven Faces of a Fatwa: Organ Transplantation and Islam' *Religions 2020*, 11(9) (2020), 1 – 22.

[183] *Professionalism and Ethics Handbook for Residents (PEHR): A Practical Guide*, p. 13.

[184] Mohammaed Ghaly, 'The Inevitable Interplay of 'Texts' and 'Context', *Bioethics*, 28 (2) (2014), https://doi.org/10.1111/bioe.12081, p. ii.

Padela identifies this third typology as ‘Muslim bioethics’. He differentiates this type with ‘Islamic bioethics’ where he considers the latter as a field anchored with ethical-legal tradition on the texts and doctrines as well as the bearer of the traditions, i.e., those who produce the texts and doctrines. Whilst ‘Muslim bioethics’ refers to sociological and anthropological study of how people act when encountering medicine and biotechnology.[185] This term indicates clearly that the third typology of actors is much debated in the discourse of Islamic bioethics.

Sherine Hamdy, an anthropologist based in University of California, Irvine, is one of those who explores this context from social and anthropological fields. She believes that the relationship of Islamic bioethics and social sciences has weakened and thus should be ‘bounced back’ to engage more productively in these disciplines’ intersections.[186] Her detailed case study of organ donation in Egypt sparks the debate on how interactions between interested parties shape the very meaning of Islamic bioethics. She argues that bioethics’ field should be ‘unbonded’ and ‘rebound’ not as an exclusive discipline but to inclusively integrate with political, economic and cultural terrains with social justice promulgation. In the Egyptian case of organ donation and transplantation, there is misrepresentation by health policy stakeholders and mass media. The policy was labelled as a clash between values of Western medical and bioethics community and the objectives of Islamic law. Whereas, the underlying concerns are about the protection of vulnerable people, the equitable distribution of organs and fair access to treatment. If the misrepresentation is left unceasing, the implementation of proper policy is hampered.

The development of bioethics in general has significant impacts at the global level. The ethical issues that Egyptians are grappling with happen elsewhere in other countries. They are not Islamic biomedical issues per se, but they are part of global problems that emerge from biomedical technology and advances. This is one of definitions given by Potter to depict global bioethics in which issues and problems affect everyone and everywhere.[187] Even that embroil other people across

[185] Aasim I. Padela, ‘Islamic Bioethics: Between Sacred Law, Lived Experiences and State Authority’, p. 72.
[186] Sherine Hamdy, *Our Bodies Belong to God*, (California: University of California Press, 2012), p. 8.
[187] Van Rensselear Potter cited in Henk ten Have, 'Global Bioethics: Transnational Experiences and Islamic Bioethics', *Zygon*, 48 (2013), p. 605.

geographical boundaries like organ trafficking through kidney-selling by people in Pakistan, a resource-low country to patients of upper income households in other country who do not wish being longer on waiting list.[188]

Resolving these issues is no longer a nation-state matter. It requires international cooperation and regulations through what is characterized by Henk ten Have as global interconnectedness. Therefore, a universal framework of bioethics is urgently needed. ten Have illustrates how Muslim scholars react to this constraint as a result of global bioethics. The political power leads Muslim scholars to contribute much in shaping and identifying global values and principles that are commonly shared by all human beings. They have been well represented at the international level, such as in UNESCO and its International Bioethics Committee drafting Universal Declaration on Bioethics and Human Rights.

The Islamic principles and values are assumed as uniform and static. Nonetheless, within the Islamic world, we might see a particular biomedical issue is attended differently from one state to another, although the same sources of law are referred to and the same context of *ijtihād's* methodologies – in case of Sunni schools of thought – is employed. It is the interaction between religious, medical and state authority that contribute to these diverse experiences and implications.

The available discourse of Islamic bioethics based on textual sources may have not work well at certain stage, and thus require different setting and mechanism. Research indicates that biomedical ethics in Islamic ethical discourse is also debated on the basis of social experiences as well as its engagement in socio-political environment by the involvement of Islamic legal authority. Clarke and Eich argue that Islamic bioethics needs to be reviewed as 'a plurality of distinctive local constellations of such national and transnational relations and project.'[189]

Globalisation is also seen in the realm of fatwa development and its interpretation that makes up different opinions among individuals, religious scholars and health care

[188] Henk ten Have, p. 606.
[189] Morgan Clarke and Thomas Eich, p. 272.

providers. The internet, for example, has in one way or another exposed individuals and communities as well as authorities to new interpretations and influences fulfilling a need for those who are searching more information which is unattainable in their domestic environment.[190] It is clear that the study of Islamic bioethics is not merely a straightforward reduction to Islamic texts on medicine and bioethical issues. Rather, as the term 'bio' itself indicates transformation of knowledge and power, it involves the roles played by the actors at various degrees. Hence, attention must be paid to social factors along with textual manifestation.

2.4. Framework of Islamic Perspectives in Deliberation of 'Disorders of Sex Development'

To reiterate, the purpose of this chapter is to identify a reliable framework for this research in order to explicate the definition of 'Islamic perspectives' as presented on the title. Until today, there is no established single set of robust principles of Islamic bioethics. The multi-dimensions of Islamic bioethics provide free and unrestricted frameworks which allow us to delve deeper into the ethico-medical issues. Yet, it is one of the challenges of this study in seeking an appropriate framework on medical issue over gender ambiguity which is still under-research from the Islamic perspectives. The framework should be comprehensive enough to cater various issues in managing patients with Disorders of Sex Development (DSD) including:

a. The implications of religious obligations upon patients with DSD.
b. Assigning specific gender for a baby with gender ambiguity.
c. Desiring gender reassignment at later age.
d. Early surgical intervention on children with DSD.
e. Autonomy in decision-making process.
f. Considering opinions and involvement of Islamic legal authority in decision-making process.

Research conducted by Ani Amelia Zainuddin and Zaleha Abdullah Mahdy discusses issues among Muslim patients with DSD from Islamic perspectives. Yet, it relies on by-product of Islamic juridical-ethical approach of classical jurists' edicts on gender

[190] Gary R. Bunt, *iMuslims Rewiring the House of Islam* (Selangor: The Other Press, 2009), p. 32.

assignment and available fatwas on sex assignment surgery.[191] Complex issues other than presented cases might be hardly resolved due to inflexibility of those texts. Whilst Mohd Salim Mohamed and Siti Nurani Mohd Noor propose utilization of Maqāṣid al-Sharīʿah as a mechanistic tool in resolving ethical dilemma of sex assignment surgery.[192] However, the study only superficially discusses the concept in comparison to the medical diagnostic, which leads to erroneous conditions as will be explained further in Chapter 5 on treatment of patients with DSD. Sayed Sikandar Shah Haneef updated his previous writings on sex assignment surgery by incorporating conditions of DSD and their ethical dilemma.[193] This paper which he co-authored with Mahmood Zuhdi Abdul Majid refers to available fatwas in Malaysia in discerning the context from medical and Islamic perspectives. They argue that if properly investigated to far-reaching juridical-ethical question it may have not been sufficiently reflected. Thus, they mention that it is important to know the subject matter or *taḥqīq al-manāṭ* as known in Islamic juridical-ethical approach.

Based on the typologies of the above-mentioned Islamic bioethics, each view consistently underlies their standpoint on the Qurʾān and Ḥadīth. In this vein, the researcher is of the opinion that this study should start with the foundational examination on Islamic perspective. A strong foundation will lend itself to a solid construction of ethos and principles in resolving the abovementioned issues of DSD. Sharīʿah, therefore, becomes the major concern to serve as the overarching framework for the whole work. Its delineation pays great attention to the higher intent of the Lawgiver (*al-Shāriʿ*), the rulings (*ḥukm*), the act (*maḥkūm fīh*) and the person (*maḥkum ʿalayh*). Sharīʿah is an Arabic word literally derived from the word *sh r ʿa* (شرع), which refers to an act of drinking.[194] Whilst sharīʿah is usually used by Arabs to describe the source of water for drinking and even for watering their animals by

[191] Ani Amelia Zainuddin and Zaleha Abdullah Mahdy, 'The Islamic Perspectives of Gender-Related Issues in the Management of Patients with Disorders of Sex Development', *Archives of Sexual Behavior*, (21 April 2016), 1-8, p. 3.

[192] Mohd Salim Mohamed and Siti Nurani Mohd Noor, 'Islamic Bioethical Deliberation on the Issue of Newborns with Disorders of Sex Development', *Science and Engineering Ethics*, 20 (25 Mar 2014), 429-440, p. 429.

[193] Sayed S. Haneef and Mahmood Zuhdi Abdul Majid, 'Medical Management of Infant Intersex: The Juridico-Ethical Dilemma of Contemporary Islamic Legal Response', *Zygon: Journal of Religion & Science*, 50 (2015), 809-829, p. 809.

[194] Ibrāhīm Muṣṭafā, Aḥmad al-Zayyāt, Ḥāmid ʿAbd al-Qādir and Muḥammad al-Najjār, *al-Muʿjam al-Wasīṭ*, vol. 1 (Dār al-Daʿwah, n.d.), p. 479.

drinking from flowing water[195]. It is also used to indicate the meaning of straight path because a source of water is a path for life and safe for health.

One of the four verses in the Qurʾān that mentions the word *sharaʿa* (the root word of sharīʿah) is translated as follow:

"… To each among you have We prescribed a law and an open way…"[196]

Based on the above verse, the 'law' (*shirʿah*) and 'way' (*minhāj*) indicate the meaning of path and way to reach a definite goal, namely the truth of religion. *Shirʿah* which brings the same meaning of sharīʿah is the source of Islamic rulings in the sense that human beings will follow the conduct prescribed within its boundary in the same way as a river flows the downstream.[197]

This word later is widely used in Islam by contemporary scholars in reference to Islamic law (*al-sharīʿah al-islāmiyyah*). Frequently, sharīʿah is linked with the ritual deeds and social life. Nevertheless, it encompasses a wider range of elements within the sharīʿah definition. Verse 13 of *Sūrah al-Shūrā* (categorised as *Sūrah Makkiyyah* which focuses on the faith and creed), expounds that the sharīʿah is related to basic principles not to the branches (*furūʿ*); and to creed not to actions.[198] This emphasis is reflected in its denotation regarding the comparable revelations that have been sent to the Prophets Nūh, Muḥammad, Ibrāhīm, Mūsā and ʿĪsā.[199] On the other hand, the word sharīʿah in verse 21 of *Sūrah al-Shūrā*, is defined as way. Sharīʿah therefore encompasses two aspects, the faith and deeds. In a broader view, sharīʿah is described by Mannāʿ Ibn Khalil al-Qaṭṭān, (d. 1999) a contemporary scholar cum judicial court of Saudi Arabia, as 'whatever is commenced by Allah for His servants in terms of doctrine, rituals performance, ethics, transactions and life management in various methods of dealing

[195] Muḥammad Ibn Mukarram Ibn Manẓūr, *Lisān al-ʿArab*, 3rd edn, vol. 8, (Beirut: Dār Ṣādir, 1414H), p. 175.

[196] The translation of the Qurʾān in ʿAbdullah Yūsuf ʿAlī, *Sūrah al-Māʾidah* (The Table Spread), 5: 48.

[197] Yūsuf Aḥmad Muḥammad al-Badawī, *Maqāṣid al-Sharīʿah ʿInd Ibn Taymiyyah*, (Jordan: Dār al-Nafāʾis, 2000), p. 8.

[198] The verse is translated as, "The same religion has He established for you as that which He enjoined on Noah - which We have sent by inspiration to thee - and that which We enjoined on Abraham, Moses, and (*cont…*) Jesus…" as translated in ʿAbdullah Yūsuf ʿAlī, *Sūrah al-Shūrā* (The Consultation), 42: 13. Yūsuf Al-Qaraḍāwī, *Madkhal Li Dirāsah Al-Sharīʿah Al-Islāmiyyah (Introduction to the Study of Islamic Law)*, 4th edn (Cairo: Maktabah Wahbah, 2001), p. 7. (See Muʿjam Al-Alfāz al-Qurʾān, Cairo: Majmaʿ Al-Lughah al-ʿArabiyyah).

[199] The verse is translated as, "What! Have they partners (in godhead), who have established for them some religion without the permission of Allah..." *Sūrah al-*Shūrā (The Consultation), 42: 21. Yūsuf Al-Qaraḍāwī, p. 7.

with relationship between men and the God and among people themselves, for seeking their betterment in this world and the hereafter'.[200]

The question now is in what way sharīʿah could be inferred in response to Islamic bioethics? 'Principles', other than *Principlism*, is also a well-known term in the study of Islamic ethico-legal tradition. Principles of Islamic jurisprudence or *ʾuṣūl al-fiqh* expound the indications and methods by which the rules of *fiqh* are deduced from the Qurʾān and Ḥadīth in prescribing *ḥukm* for such deeds.[201] *ʾUṣūl al-fiqh* is widely known as a discipline coherently developed by al-Shāfʿī (d. 204 AH/820 CE), a leading scholar in Sunni Shāfʿiyyah school of thought. In fact, similar methodology was used by other scholars afore him. But al-Shāfiʿī successfully found huge debates of juristic thoughts and argumentations on methodological issues.[202]

According to Hashim Kamali, a prominent contemporary scholar in Islamic law, *ʾuṣūl al-fiqh* is vital in order, firstly to regulate *ijtihād* and guide jurists in deducing the law. Secondly, to help the jurist to obtain adequate knowledge of the sources of sharīʿah and of the methods of juristic deduction and inference. Thirdly, to help the jurist to distinguish which method is the best suited in obtaining rulings of a particular issue. Fourthly, to assist the jurist to ascertain and compare strength and weakness in *ijtihād* and give preference to that ruling. Lastly, this discipline able to alleviate the scholar's anxiety towards erroneous and confusion in deducing such rulings especially by those unqualified persons who attempted in carrying out *ijtihād*.[203]

This discipline encompasses several methodologies including *ijmāʿ* (consensus of Muslim jurists) and *qiyās* (analogical reasoning) which are unanimously agreed by the Companions, the Followers (*al-tābiʿīn*) and Muslim jurists as the proof (*ḥujjah*) in Islamic law.[204] *Ijmāʿ* refers to consensus of Muslim jurists regarding specific issues on which no clear guidance in the Qurʾān and Ḥadīth. While *qiyās* refers to the act of

[200] Mannāʿ Ibn Khalil al-Qaṭṭān, *Tārīkh al-Tashrīʿ al-Islāmī (History of the Islamic Law)*, (Cairo: Maktabah Wahbah, 2001), p. 13.

[201] Mohammad Hashim Kamali, *Principles of Islamic Jurisprudence*, Revised edn (Cambridge: The Islamic Text Society, 1991), p. 12.

[202] Mohammad Hashim Kamali, *Principles of Islamic Jurisprudence*, p. 12.

[203] Mohammad Hashim Kamali, *Principles of Islamic Jurisprudence*, p. 13.

[204] Badr al-Dīn Muḥammad al-Zarkashī, *Baḥr al-Muḥīṭ fī ʾUṣūl al-Fiqh (the Vast Explanation of the Principles of Islamic Jurisprudence)* (Al-Ghardaqah: Dār al-Ṣafwah, 1988), vol 4, p. 436.

appending the new case (*farʿ*) that has no specified verse of the ruling found in the Qurʾān or Ḥadīth to the original case (*aṣl*) that has been explained in either or both of the sources in term of the ruling. Besides, there are other methodologies which are debated among Sunni Schools of thought namely *istiḥsān* (juridical preference), *maṣlaḥah al-mursalah* (public interest), *ʿurf* (custom), *qawl al-ṣaḥābiy* (Companion's opinion), *sadd al-zarāiʿ* (blocking means) and *istiṣḥāb* (continuity). Each methodology has its own characters that enrich the technique of analysis over issues that are silent in the Qurʾān and Ḥadīth. The most prevalent mechanism used in the present day is *maṣlaḥah al-mursalah* as it provides a flexible and broad-spectrum way of viewing current and complicated issues.

On the other hand, the scholars of Ḥanāfī have attempted to expound *ʾuṣūl al-fiqh* in conjunction with the *fiqh* itself. Besides, many of them pioneered a different methodology known as Islamic legal maxims (*al-qawāʿid al-fiqhiyyah*). The legal maxims are inductively derived from the existing rulings on the basis of prevalent cases. When, for example, there is a conflict between the principle of *ʾuṣūl* and the principle of *fiqh*, Ḥanāfī scholars make adjustment to theory so the conflict is removed or make necessary exception to reach a compromise.[205] The numbers of legal maxims proliferated over the centuries. This methodology was established to solve specific issues by upholding the wisdom of sharīʿah; to secure the benefits and to avoid any harm. It is therefore, used to gain in-depth understanding in such situations and is not to be regarded as an act of law.[206] From the hundreds of legal maxims now existing, there are five primary *qawāʿid al-fiqh* which become central to its notion known as: i), all affairs are judged by their intention; ii) certainty is not removed by doubt; iii) difficulty gives rise to ease; iv) harm is to be removed; and v) the rule is by custom.[207]

The first principle, all affairs are judged by their intention, comprises several sub principles. This sub principle calls upon the physician to be fully aware of his/her actions, either seen or unseen, so that the action is rewarded by Allah fairly.[208]

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[205] Mohammad Hashim Kamali, *Principles of Islamic Jurisprudence*, p. 18.

[206] ʿIzzat ʿAbd al-Daʿās, *al-Qawāʿid al-Fiqhiyyah Maʿ al-Sharḥ al-Mūjaz*, 3rd edn. (Beirut: Dār al-Tirmizi, 1989), p. 7.

[207] Jalāl al-Dīn ʿAbd al-Raḥman al-Suyūṭī, *al-Ashbāh wa al-Naẓāʾir fī Qawāʿid wa Furūʿ Fiqh al-Shāfiʿiyyah (Plausible and Identical in Methodologies and their Branches of Shāfiʿī School of Thought)* (Beirut: Dār al-Kutub, 1983), p. 7-8.

[208] Omar Kasule, *The Legal and Ethical Basis of Medical Practice*, p. 6.

Secondly, the principle ‘certainty is not removed by doubt’ is unachievable from the standard legal side. However, in medicine the certainty can be based on the best level of probability to carry out such treatment. Consequently, the working diagnosis should be continued until and unless there is enough evidence to form new practices and treatment. The third principle ‘difficulty gives rise to ease’ implies that whenever hardship occurs, in preserving necessities, a prohibited action can be permissible. The measurement of the hardship is definitely should be based on the level of necessities where one or more of the five elements, i.e. faith, life, mind, offspring or wealth is at risk.

The fourth principle ‘harm is to be removed’ is the most common principle referred to in biomedical issues. Basically, medical intervention is justified through this principle in order to alleviate the illness. Its sub principles are useful to clarify the dilemma of a clash between two harms, the manner of removing the harm and the clash between the permissible and the forbidden effects. The last primary principle ‘the rule is by custom’ is closely related to the principle of jurisprudence (*uṣūl al-fiqh*); *ʿurf*. Custom has a legal impact so long it does not contravene the sharīʿah. A precedent case which is uniform, widespread, predominant and not rare can be referred to as legal customary stance.[209] While it is inappropriate to list all the sub-principles under these five major principles, they will be introduced and explained along with the discussion of bioethics in this thesis.

Both *ʾuṣūl al-fiqh* and *qawāʿid al-fiqh* form the basis of legal impact which is entirely comprised of ethical and moral standard. Deducing such rulings directly from the texts or based on indications or evidence through *ijtihād* mechanisms does not rigidly provide the 'dos and don’ts’. Between them are five categories of accountability rulings (*ḥukm al-taklifi*) including obligatory (*wājib*), recommended (*mandūb*), permissible (*mubāḥ*) and forbidden (*ḥarām*). Both methodologies also provide legal and moral judgement on what is defined as good and bad in the light of Divine guidance.

Above all, the principles of Islamic jurisprudence and legal maxims are nothing but as means to achieve the higher purpose of sharīʿah (*maqāṣid al-sharīʿah*). The notion of

[209] Omar Kasule, *The Legal and Ethical Basis of Medical Practice*, p. 7.

the objective of sharīʿah was not properly developed until the 5th Islamic century.[210] The limitation of *qiyās* (one of the mechanisms of deducing a ruling as will be discussed later) in response to the new cases led to the emergence of the concept 'unregulated interest' (*maṣlaḥah al-mursalah*). This concept later expanded as a theory in understanding the wisdom behind the sharīʿah.[211] As explained before, this concept was interchangeably used with *maṣlaḥah* or its technical term; *istiṣlāḥ.* The development in employing the concept of *maṣlaḥah* was found in 2nd and 3rd Islamic century, as mentioned by Felicitas Opwis.[212] It was al-Khawarizmi (d. after 387 AH/997 CE) who employed *istiṣlāḥ* as one of the proofs on injunctions that was attributed to the Mālikī's school. Another work of Ḥanāfī's school was also found in Abū Bakar al-Jaṣṣāṣ's scripture (d. 370 AH/980 CE) although in unclear manner.[213]

The concept of *maṣlaḥah* was extended in the formation of three-level-*maqāṣid*, which had been done by Abū al-Maʿālī al-Juwaynī (d. 478 AH/1085 CE). His theory was expanded by al-Ghazālī, who initiated the five elements of preservation of sharīʿah. ʿIzz al-Dīn ʿAbd al-Salām (d. 660 AH/1209 CE), Shihāb al-Dīn al-Qarāfī (d. 684 AH/1285 CE), Shams al-Dīn Ibn al-Qayyim (d. 748 AH/1347 CE) and most significantly, Abū Isḥāq al-Shāṭibī (d. 790 AH/1388 CE) are among the scholars until 8th Islamic century who contributed very much to developing the understanding of *maqāṣid*. From only a few paragraphs of explanation, this notion developed to be a dynamic foundation as found in numbers of books across various field such as economic, law, social policy and medicine.

Maqāṣid al-sharīʿah is deeply rooted in the understanding of the fulfilment of the public interests and the avoidance of mischief (*jalb al-maṣāliḥ wa daf*ʿ *al-mafāsid*). *Maṣlaḥah* (or *maṣāliḥ* in plural) is also translated as benefits, where the good and bad, morals and ethics, are analysed within this theory. Al-Ghazālī views *maqāṣid al-sharīʿah* in the totality of the concept of public interests. On top of that, public interests, as Al-ʿIzz and al-Shāṭibī highlight, is for the benefit of the worshippers in both this world and the

[210] Jasser Auda, *Maqāṣid Al-Sharīʿah as Philosophy of Islamic Law - A System Approach*, Special edn (Selangor: Islamic Book Trust, 2010), p. 17.
[211] Jasser Auda, *Maqāṣid Al-Sharīʿah as Philosophy of Islamic Law*, p. 17.
[212] Felicitas Opwis, 'Maṣlaḥa in Contemporary Islamic Legal Theory', *Islamic Law and Society*, 2(2005), 182 – 223, p. 188.
[213] See further in Aḥmad Ibn ʿAlī al-Jaṣṣāṣ, *Al-Fuṣūl fī al-ʾUṣūl*, (Kuwait: Wizārah al-Awqāf al-Kuwaytiah, 1994).

hereafter.[214] The universal characteristic of sharīʿah enables it to be applied to various fields, let alone the medical field. Al-ʿIzz describes the purpose of medical treatment as identical to the objective of sharīʿah, i.e. to secure the benefits of safety and wellness and to prevent the harms of injury and sickness.[215]

It is arguable to really understand the objectives of sharīʿah since the authority relies on Allah as the Lawgiver. Therefore, al-Ghazālī for example refused to acknowledge the principle of 'public interests' that are seemed to be illusionary (*al-uṣūl al-mawhūmah*), as he coined it, unless they are identified by means of the Qurʾān, Ḥadīth and *ʾijmāʿ*.[216] Perhaps, his adherence to the Shāfiʿī methodology which strictly depends on *qiyās* strengthens his meticulous analysis. Presumably, it is to avoid any individual inclination or preference in defining 'interests', hence deviate from the real objectives of sharīʿah. Al-ʿIzz adds that the definition of *maṣlaḥah* is basically based on strong assumption to achieve the betterment for this world and the hereafter.[217] It is based on the verse of the Qurʾān: "…And whatever good ye send forth for your souls before you, you shall find it with Allah…"[218]

The term of *maqāṣid al-sharīʿah* is not clearly defined until Moḥammad Ṭāhir Ibn ʿAshūr (d. 1973), among pioneers of *maqāṣid al-sharīʿah* gives its definition as the purposes and wisdoms behind enactment of all or most of sharīʿah rulings which are not bounded on any specified rulings.[219] Hence, the means or mechanisms of *ijtihād* are adjustable to achieve the higher objectives of sharīʿah as proposed by Auda.

Contemporary scholars suggest a new dimension of the elements that should be protected. For instance, Tariq Ramadan suggests that a higher intent of the sharīʿah should be expanded for promoting and protecting dignity, welfare, knowledge,

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[214] Abū Isḥaq Ibrāhīm ibn Mūsā al-Shāṭibī, *al-Muwāfaqāt fī Uṣūl al-Aḥkām*, vol. 2 (Cairo: Dār Aḥyāʾ al-Kutub al-ʿArabiyyah), p. 8.

[215] ʿIzz al-Dīn ibn ʿAbd al-Salām, *Qawāʿid al-Aḥkām fī Maṣāliḥ al-Anām,* ed. by Ṭaha ʿAbd al-Raʾuf Saʿd, vol. 1 (Cairo: Maktabah al-Kulliyyāt al-Azhariyyah, 1991), p. 6.

[216] Abū Ḥāmid Muḥammad ibn Muḥammad al-Ghazālī, pp. 502-503.

[217] ʿIzz al-Dīn ibn ʿAbd al-Salām, p. 5.

[218] The translation of the Qurʾān in ʿAbdullah Yūsuf ʿAlī, *The Holy Qur´an Text, Translation and Commentary*, New Revised edn (Brentwood: Amana Corporation, 1989). *Sūrah al-Baqarah* (The Heifer), verse 2: 110.

[219] Al-Ṭāhir Ibn ʿAshūr, *Maqāṣid al-Sharīʿah al-Islāmiyyah (Objectives of Islamic Jurisprudence),* ed. by Muḥammad al-Ṭāhir Al-Mīsāwī (Jordon: Dār al-Nafāʾis, 2001).

creativity, autonomy, development, equality, freedom, justice, fraternity, love, solidarity and diversity.[220] In this study, the original objectives five of the protected elements will be indicated, as their foundation is unarguable and widely accepted. *Maqāṣid al-sharīʿah* remains the main focus even the Islamic juridical ethical traditions are referred to in exploring Islamic perspectives over ethical issues such as gender assignment and the ensuing treatment.

On another occasion, the standpoint made by scholars like Padela, Morgan and Eich on the importance of roles of actors is not bizarre in Islam. Sharīʿah does give attention to human as the actor. In Islamic law, a person is not only the actor but a person whose act invokes a *ḥukm* or the subject of which *ḥukm* requires him to act in prescribed manner. The person also those who possess legal capacity whether he/she acts directly or through delegated authority. The person is called as *mukallaf* in Islamic jurisprudential views which gives balanced weightage on the rights and obligations in carrying out duties as Muslims. Therefore, issues on autonomy and the rights in decision-making process are undertaken in sharīʿah perspective. Similarly, the roles play by family, community and legal authority are all the more important in shaping the Islamic fundamentals of biomedical ethics.

In sum, it has been demonstrated that sharīʿah ties the relationship between human and God and thus guides humans in defining and distinguishing between good and bad, benefits and harms as prescribed in the Qurʾān, Ḥadīth and *ijtihād.* The deliberation of sharīʿah forms legal discretion that steer moral and ethical conducts and interactions among humans themselves. Hence, sharīʿah is itself a legal and ethical framework that governs the whole concept of Islamic biomedical ethics.

2.5. Conclusion

The main pillar of this study is to evaluate the Islamic perspectives pertaining to a medical issue. The word ‘perspectives’ may imply the state of ‘understanding of how

[220] Tariq Ramadan, *Radical Reform: Islamic Ethics and Liberation* (Oxford: Oxford University Press, 2009), p. 140.

important things are in relation to others'.[221] In order to achieve this understanding, clear manifestation is identified on what is constituted in the Islamic perspectives. The researcher is of the opinion that a robust framework is vital in disentangling any ethical issues in a medical setting and of which can be adapted later within various cultural backgrounds and practices particularly among Muslim societies. More specifically, the aim is to provide a durable and congruent framework for discussing ethical issues in Disorders of Sex Development (DSD) in later chapters.

Hence, sharīʿah is recognised as a holistic approach and become the framework of this research. This single research may not be able to propose sharīʿah as the sole tool in resolving bioethical issues. However, it might indicate the extent of its flexibility, by taking into account the very foundational ground of Islamic edict, in discussing complex issues of gender ambiguity. The following discussions in Chapter 3 to Chapter 7 are more thought-provoking as multi-disciplinary deliberations will take place involving the pragmatism of sharīʿah and the controversial ethical dilemma in medical settings.

[221] *Oxford Paperback Dictionary and Thesaurus*, ed. by Maurice Waite and Sara Hawker, 3rd edn (New York: Oxford University Press, 2009), p. 682.

3. *KHUNTHĀ* AND DISORDERS OF SEX DEVELOPMENT: ARE THEY IDENTICAL?

3.1. Overview

This chapter explores the first objective of the research, i.e. on the relationship, if any, between *khunūthah* and Disorders of Sex Development (DSD). Research was conducted to understand common sexual development from hermeneutic study and biological development based on Islamic and medical perspectives, respectively. This will lead to better understanding of abnormalities in sexual development that contribute to the notion of *khunūthah* and DSD from both Islamic and medical perspectives that indicate the two different perspectives on gender and sex outside of the two normative genders (male and female). The development of the notion of *khunūthah* was studied in classical and contemporary approaches, followed by a study on DSD and its variants. This exploration informs this study on the importance of redefinition of *khunūthah*, as explained at the end of this chapter. It is because the classical definition emphasizes merely external genital appearance whereas the new definition considers biological condition to avoid any misinterpretation of hermaphroditism from the Islamic perspectives.

Khunthā, as will be thoroughly explained in subtopic 3.3 of this chapter, is translated as hermaphrodite in English. The condition of hermaphroditism is referred to as *khunūthah*. However, more often than not the term *khunthā* is used to denote both the condition and the individuals who are affected by it. However, the term hermaphrodite in itself is being contested in contemporary sociology and medical debates. Therefore, to avoid any misleading or misinterpretation throughout this thesis, the term *khunthā* is used to refer to the affected individuals; or the term *khunūthah* to denote the condition that has been discussed by Muslim scholars. It is also an objective of this research to identify the relationship between *khunthā* and DSD. Therefore, using the term *khunthā* is self-justified.

3.2. Gender in Islamic and Biomedical Frameworks

> "O mankind! Indeed We created you from a single (pair) a male and a female, and made you into nations and tribes, that you may know each other…"[222]
>
> "…And from them twain scattered (like seeds) countless men and women".[223]
>
> "…He (Allah) bestows male (children) to whom He wills and He bestows female (children) to whom He wills. Or He bestows both males and females…"[224]

These Divine texts show that human beings are subsumed into two categories as becoming either male or female. The dichotomy of two genders is perceived through numerous ethico-legal texts from the Qurʾān and the Ḥadīth. For instance, such matters involving the allocation of inheritance, a portion for male is equal to two portions for a female; and that of the covering the ʿ*aurah* (modesty) so as not to exceed women beyond what is acceptable to be revealed and considering having the witnesses of two women as being equal to one man as witness.[225] None of the Qurʾanic texts are found to have categorically mentioned *khunthā* in any given juridical situation and of it being bound to specific rules. There are very few traditions mentioned about *khunthā* and these are limited to legal jurisdictions on inheritance. Jurists in this sense put so much legal efforts to accommodate them and to offer pragmatic solutions for dealing with them while simultaneously acknowledging their status and role in society and also creating a sense of acceptance of their presence within the realms of the society.[226]

The term *al-zakr* (male) and *al-unthā* (female) are mentioned repeatedly in the Qurʾān, as shown above, confirming the two types of genders. In respect of this standpoint, it is reported that the existence of *khunthā*, whose external genitalia are ambiguous, was rejected by a specific group of people. For Muḥammad Abū Ḥayyan (d. 745 AH/1344

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[222] The translation of the Qurʾān, in ʿAbdullah Yūsuf ʿAlī, *The Holy Qur'ān Text, Translation and Commentary*, New Revised edn (Brentwood: Amana Corporation, 1989). *Sūrah al-Ḥujurāt* (The Chambers), 49: 13.

[223] The translation of the Qurʾān, in ʿAbdullah Yūsuf ʿAlī, *Sūrah al-Nisāʾ* (The Women), 4: 1

[224] The translation of the Qurʾān, in ʿAbdullah Yūsuf ʿAlī, *Srah al-Shūrā* (The Consultation), 42: 49-50.

[225] See in the Qurʾān *Sūrah al-Nisāʾ* (The Women), 4: 11 for inheritance; *Sūrah al-Nūr* (The Light), 24: 30 for modesty; and *Sūrah al-Baqarah* (The Heifer), 2: 282 for male and female witnesses.

[226] Vardit Rispler-Chaim, *Disability in Islamic Law*, ed. by David N. Weisstub and Thomasine Kimbrough Kushner (Dordrecht: Springer Netherlands, 2006), p. 71.

CE), Divine-inspired-categorization of gender denies the existence of *khunthā* and therefore any ambiguity should be assigned to either one of the genders.[227] However, this argument has been criticized by the majority of the scholars as denoting Abū Ḥayyan lack of unacquaintance with linguistics, his ignorance of the eloquent and limited understanding of God's all-encompassing power.[228]

Based on a hermeneutic study of text on revelations, *al-zakr* and *al-unthā* are identified as general texts (*lafẓ ʿām*) encompassing all types under this category without any limitation or any particularity. The existence of *khunthā* cannot be disregarded as a proof of Allah's infinite power as He mentions in the verse 49, *Sūrah al-Shūrā* about His ability to create any creatures based on His will to bestow male and female children to whom He wills.[229]

Grammatically, in Arabic, a gender-accentuated-language, *khunthā* is classified as masculine. But this is not the case in real situations. By accepting the status of *khunthā,* it becomes a challenge for a binary gender system to place this 'third category' in its strict boundary. Should this system be compromised to accommodate *khunthā* in their own society? Presently, people with gender ambiguity are facing difficulties, given the discursive contestation between religion, biomedicine and human rights discourses.[230] It is crucially important to explicate here in relation to later discussions on gender assignment. In the process of *analysing* this question, critical reference has been made towards commentaries of the Qurʾān where the Qurʾanic source of this system is concerned.

Understanding the intention of the Lawgiver is not a straightforward process. The linguistic rules that govern the origin of words, their usage and classification have become instrumental aids to the correct understanding of sharīʿah, which is also

[227] Abū Ḥayyan, Muḥammad ibn Yūsuf, *Al-Baḥr Al-Muḥīṭ fī Al-Tafsīr (the Encompassing Ocean in Commentary)*, ed. by Ṣidqī Muḥammad Jamīl, vol. 3 (Beirut: Dār al-Fikr, 1420), p. 496.

[228] Abū ʿAbd Allah Al-Qurṭubī, *Al-Jāmiʿ Li Aḥkām Al-Qurʾān (the Compiler for Qurʾanic Rulings)*, ed. by Aḥmad Al-Bardūnī and Ibrāhīm Aṭfīsh, 2nd edn, vol. 16 (Cairo: Dār al-Kutub al-Miṣriyyah, 1964), p. 51.

[229] The translation of the Qurʾān in ʿAbdullah Yūsuf ʿAlī, *Sūrah al-Shūrā* (The Consultation), 42: 49 – 50.

[230] Saskia E. Wieringa, 'Gender Variance in Asia - Discursive Contestations and Legal Implications', *Gender, Technology and Development*, 14 (2010), 143-172, p. 163.

known among *ʾuṣūliyyūn* (experts in the discipline of principles of Islamic jurisprudence) as *al-qawāʿid al-lughawiyyah* (linguistic methodologies).[231]

One of the fundamental aspects in applying the principles of Islamic jurisprudence is to be able to differentiate between the general (*ʿām*) and the specific (*khāṣ*) words in the Qurʾanic grammatical usage as briefly mentioned in Chapter 2 on sources of sharīʿah. *Al-ʿām* refers to the term illustrating certain meanings, consisting of many things, including unrestricted elements and which can be recognized through the term either intrinsically or by its context.[232] In six formulas identifying the term *ʿām* is the presence of the article '*al*' preceding singular Arabic words.[233] Thus, the grammatical and contextual forms of the abovementioned verses obviously identified the terms *al-zakr* and *al-unthā* as *ʿām* or general terms.[234] Human gender therefore is classified into two categories, i.e. male and female. Consequently, a *khunthā* who is biologically not exactly demarcating precisely between being a male or a female, is subcategorized under these two categories.

The majority of Sunni jurists are in agreement with the commentators, by mercy of such linguistic rules. Several points that can be listed here are firstly, human beings are either male or female. Secondly, the existence of *khunthā*, mainly the discernible *khunthā* (one of the two types of *khunthā* that will be discussed later) is recognized by the majority of the jurists. Though the existence of intractable *khunthā* is disputed among a few scholars such as al-Ḥasan al-Baṣrī, among the *tābʿīn* (the Followers after the generation of the Companions) and al-Qāḍī Ismāʿīl, a Maliki scholar.[235] Thirdly, the *khunthā* are unanimously not regarded as a third gender based on the arguments of jurists of the four schools of thought.[236] This is based on linguistic and juridical

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[231] Mohammad Hashim Kamali, *Principles of Islamic Jurisprudence*, Revised edn (Cambridge: The Islamic Text Society, 1991), p. 86.

[232] Muḥammad Muṣṭafā Shalbī, *Uṣūl Al-Fiqh Al-Islāmī (the Principles of Islamic Jurisprudence)* (Beirut: Dār al-Nahḍah al-ʿArabiyyah, 1987), p. 409.

[233] Other five formulas including the presence of: i) article '*al*' prior to plural words; ii) the relative nouns; iii) interrogative nouns; iv) protasis nouns; and v) indefinite nouns in negation, protasis or proscription form.

[234] Mohammad Kamali, *Principles of Islamic Jurisprudence*, p. 106.

[235] Al-Ḥaṭṭāb al-Ruʿīnī, Muḥammad ibn Muḥammad, *Mawāhib Al-Jalīl fī Sharḥ Mukhtaṣar Khalīl (The Majestic Gift of Compendium Partner)*, 3rd edn, vol. 6 (Dār al-Fikr, 1992), p. 424.

[236] Al-Shanqiṭī, Muḥammad al-Amīn ibn Muḥammad al-Mukhtār, *Aḍwāʾ Al-Bayān fī Iḍāḥ Bi Al-Qurʾān (Shedding Lights in Brightness with the Qurʾān)*, vol. 3 (Beirut: Dār al-Fikr, 1995), p. 336; Al-Ḥaṭṭāb al-Ruʿīnī, Muḥammad ibn Muḥammad, vol. 6, p. 424; Ibn Muḥammad Zakariyā Al-Anṣarī, *Al-Gharar Al-Bahiyyah Fi Sharḥ Al-Bahjah Al-Wardiyyah (A Pleasant Uncertainty in Elucidating the Rosacea Splendor)*, ed. by Al-

approaches, in which occasional cases (*al-nādir*) are recognized under the general terms (*al-ʿumūmāt,* plural form of *al-ʿām*) or under frequent circumstances (*al-ghālib*) respectively.

Although the source of scripture is undeniably firm, the exegesis of the scholars are subjects for discussion. Could the gender determination, mentioned in the Qurʾān, be in harmony with an empirical study such as biology? Hence, from the religious corpus study, we shall move on to another different spectrum, biomedical terms. Biomedical terms are introduced here, early in this thesis, as it will help towards gaining a clearer understanding in later chapters when discussing the conditions of DSD.

Ibn Sīnā, a Muslim physician in the 10th century once mentioned that there are two elements known as male and female, discerned by the presence or absence of testes, for survival of the sexes in mammals including human beings.[237] Not until 1604 was a study of human biology conducted by Girolamo Fabrizio (d. 1619) explaining in detail the subject of embryology.[238] After more than two centuries, in 1865, Gregor Mendel (d. 1884) successfully came out with a new theory on heredity as the foundation of genetics.[239] However, only after his death, was his study expanded by Walter Stanborough Sutton (d. 1916) in 1903, on chromosomes.[240] At the same time, Wilhelm Ludvig Johannsen (d. 1927), in support of Mendel's study, introduced the concepts of 'gene', 'genotype' and 'phenotype'. We shall also be looking into chromosomes, genotypes and phenotypes and their roles in human sexual development.[241]

Chromosomes play an essential role in sex determination in mammals, including human beings. Human chromosomes contain 22 pairs of autosome chromosomes and

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ʿAllāmah al-Sharbīnī, Ḥāshiah Al-Sharbīnī , vol. 1 (Egypt: Maṭbaʿah al-Maymaniyyah, n.d.); ʿAbdullah Aḥmad Ibn Qudāmah, *Al-Mughnī (the Enricher)*, vol. 7 (Cairo: Maktabah al-Qāhirah, 1963), p. 207.

[237] Al-Ḥusayn ibn ʿAli ibn Sīnā, *Al-Qānūn fī Al-Ṭibb*, ed. by Muḥammad Amīn al-Ḍannāwī, vol. 1 (Beirut: Dār al-Kutub al-ʿIlmiyyah, 1999), p. 39.

[238] Lesile T. Morton and Robert J. Moore, *A Chronology of Medicine and Related Sciences* (Aldershot: Ashgate, 1997), p. 35.

[239] Charlotte Auerbach, *The Science of Genetics* (London: Hutchinson & Co., 1962), p. 10.

[240] Lesile T. Morton and Robert J. Moore, p. 35.

[241] Genotype refers to 'the total gene outfit of an organism, including the way the genes are arranged on the chromosomes'. Whilst phenotype refers to the human's appearance including numerous characteristics of his/her body and mind. See more in Charlotte Auerbach, p. 33.

a pair of sex chromosomes.[242] Sex chromosomes have been studied in Drosophila larvae due to their large size and because the same sex chromosome the element is also found in human beings.[243] Based on the studies, we know that there are two different pairs of sex chromosomes in which the development of these sex chromosomes determines the two sexes, male and female. Due to the very essence of how people differ, this biological model is also known as essentialist in gender discourses.[244] Evidently, human beings are divided into two sexes.

The differences between the two sexes continue to develop from one stage of growth to another throughout the course of human biological development. The first stage of differentiation is known as sex determination.[245] It is recorded that each human being carries at least X chromosomes, inherited from the mother. The difference in sex chromosomes lies on the second pair, in which X chromosomes are carried in all cells of a woman, while Y chromosomes are carried in all cells of a man. Therefore, in any typical case, a woman has in her body 46,XX sex chromosomes and a man has in his body 46,XY chromosomes.[246] This occurrence of sex determination occurs in accordance to Mendel's first law and is completed at the time of conception.[247]

The next stage of human sexual development is known as sex differentiation, in which the differentiation involving internal and external genitalia persist for the male and female. It is the process where genetically determined sex is translated into structures, functions and behaviour patterns as internal reproductive structures and external genitalia.[248] It occurs in three stages, which are gonadal, ductal and external genital differentiation. At the gonadal differentiation stage, a bipotential gonad develops into either an ovary for the female or a testis for the male.[249]

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[242] N. Islam, 'Elements of Chromosome Abnormalities', *Postgraduate Medical Journal*, 40 (1964), p. 194. An autosome chromosome is not a sex chromosome and occurs in pairs in diploid cells.

[243] Charlotte Auerbach, p. 102

[244] Simona Giordano, *Children with Gender Identity Disorder - A Clinical, Ethical and Legal Analysis* (New York: Routledge, 2013), p. 37.

[245] Charlotte Auerbach, p. 104.

[246] SF Gilbert, 'Chromosomal Sex Determinations in Mammals', in *Developmental Biology*, 6 edn (Sunderland: Sinauer Associates, 2000), 1 <http://www.ncbi.nlm.nih.gov/books/NBK9967> [accessed 1 May 2016], para 1 of 29.

[247] Charlotte Auerbach, p. 104

[248] Charlotte Auerbach, p. 104; Tuck C. Ngun and others, 'The Genetics of Sex Differences in Brain and Behavior', *Frontiers in Neuroendocrinology*, 32 (2011), 227-246, p. 233.

[249] Tuck C. Ngun and others, p. 233

This leads to the formation of a duct whereby in the absence of Y chromosomes, ovaries are developed to produce a hormone to enable the development of the Müllerian duct into the uterus. In contrast, with the presence of Y chromosomes, the testes are developed and two hormones are secreted, i.e. the Anti Müllerian duct Hormone (AMH) and testosterones. The AMH suppresses the growth of the Müllerian duct, whilst the testosterone stimulates the formation of the Wolffian duct and leads to the formation of the male external genitalia and other related anatomy parts.[250]

Subsequently, the formation of the Müllerian duct leads to the formation of the vagina for the female. However, in the male line, a hormone produced by the testes stimulates the formation of a penis, the scrotum and the prostate.[251] These are the biological developments that happen in the formation of human sexual development in normal cases. 'Normal' in this sense is referred to as 'that which function is in accordance with its design' as defined by C. Daly King and was later used by Kenneth J. Zucker in his explanation about intersexuality.[252]

Figure 3, designed by the researcher herself, shows the overall process in a simplified version. This figure is not clinically precise and inclusive since this research is not meant for medical studies. The importance here is to emphasize the keywords and the main processes especially in relation to the understanding of abnormalities in sexual development that form the heart of this research.

[250] SF Gilbert, para 4 of 29; Swornya Krishnan and Amy B. Wisniewski, 'Ambiguous Genitalia in the Newborn', in *Endotext [Internet]*, ed. by L. J. De Groot and others (South Darmouth (MA): MDText.com, Inc., 2000-) <http://www.ncbi.nlm.nih.gov/books/NBK279168> [accessed 26 May 2016], para 8 of 48.

[251] SF Gilbert, para 5 of 29, Swornya Krishnan and Amy B. Wisniewski, para 9 of 48; Nasir A. M. Al-Jurayyan, 'Disorders of Sex Development: Diagnostic Approaches and Management Options - an Islamic Perspective', *Malaysian Journal Medical Science,* 18 (Jul - Sep 2011), 4-12, p. 5.

[252] C. Daly King, 'The Meaning of Normal', *Yale Journal of Biology and Medicine,* 17 (January 1945), 493 – 501, p. 494; Kenneth J. Zucker, 'Intersexuality and Gender Identity Differentiation', *Annual Review of Sex Research,* 10 (1999), 1- 69, p. 41.

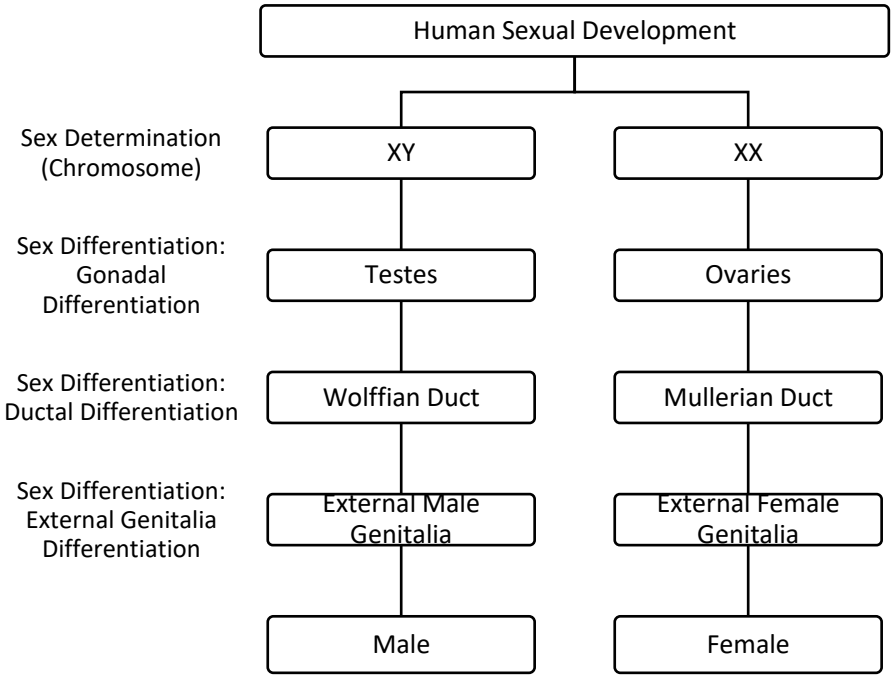

Figure 3: Simplified Model for Sexual Determination and Sexual Differentiation

The sex differentiation process continues throughout embryonic development, childhood and adolescence. Classical views, like those of Jost and Gilbert, believe that the differentiation is driven by gonadal hormones. However, a recent study shows that genes in the sex chromosomes also contribute to this differentiation, constructed thus by the brain.

'Sexual differentiation is an orderly sequential process' in which any deficiency at any stage can cause some *disorder* affecting the process and would then lead to sexual ambiguity.[253] Charlotte Auerbach states that intersexuality may be due to abnormal chromosome constitution and hormonal disturbance.[254] These, in turn, contribute to ambiguous genitalia, placing an affected individual in gender ambiguity. The scenario may be noticed earlier in infancy or may be traced later on, in adulthood. This is one of a number of crucial points in this research that will be discussed further in subtopic

[253] Nasir A. M. Al-Jurayyan, 'Ambiguous Genitalia: Two Decades of Experience', *Annals of Saudi Medicine*, 31 (May - Jun 2011), 284-288, p. 285.
[254] Charlotte Auerbach, p. 104.

3.4 on how these abnormalities could occur. It is sufficient to note in this introduction, that gender ambiguity is the result of imperfections of initial sexual differentiation. Variations of inconsistent atypical occurrences justify that gender ambiguity is not in fact another type of gender.

This argument is challenged by some scholars, including by the biologist Anne Fausto-Sterling, the bioethicist Simona Giordano, the psychiatrist B. Cordier and the sociologist Saskia E. Wieringa. Emphatically focusing on the rights of transgender people – in broad meaning –, Wieringa suggests the need for a cultural discourse producing a different set of truth claims against the biomedical perspective. Giordano, in her study on biological sex, claims that the simple 'two sexes only' theory as a misrepresentation of more complex occurrences.[255] Cordier claims that the duality in our species has Manichean aspects (i.e. conflict between two opposite sexes), in which he may agree with Fausto-Sterling's idea of five-sex, namely, the males, females, 'herms' (referring to 'true' hermaphrodites), 'merms' (referring to male pseudo-hermaphrodites) and 'ferms' (referring to female pseudo-hermaphrodites).[256]

The discursive contestations on sex and gender from various perspectives make it delicate to be understood. It is 'difficult to disentangle the relative contribution of biological and psychosocial influences' according to Zucker.[257] However, even after so much effort put to legitimise the intersexuality's state of nature, there are still loopholes for further discussion. Leonard Sax argues in response to Fausto-Sterling's view that human sexuality is a dichotomy and not a continuum, especially given that the percentage of intersex occurrences is low and not a common phenomenon.[258] Hence, 'the third gender' among physicians is not an attractive option within their binary model.[259] In spite of this, it is not the intention of this research to engage in the discussion about the status of transgender or to delve deeper into the debates. To discuss this would demand more time and effort and would require another type of

[255] Saskia E. Wieringa, p. 146, Simona Giordano, p. 25.

[256] B. Cordier, 'Gender, Betwixt Biology and Society', *Sexologies*, 21 (2012), 192-194, p. 194; Anne Fausto-Sterling, *Sexing the Body* (New York: Basic Books, 2008), p. 78. Please refer to subtopic 3.4 in this chapter for further clarification on the terms of male pseudo-hermaphrodites and female pseudo-hermaphrodites.

[257] Kenneth J. Zucker, 1999, p. 5.

[258] Leonard Sax, 'How Common is Intersex? A Response to Anne Fausto-Sterling', *The Journal of Sex Research*, 39 (August 2002), 174-178, p. 177.

[259] Saskia E. Wieringa, p. 148.

research project. It is sufficient to note that persons with DSD are facing health risks and biological disturbances and that any sex change, if required, should not merely be based on psychological interest. In contrast, transgender refers to those who move between male or female gender identities or attempt to occupy a third gender category. They challenge the strict gender dualism operative in much more anthropological terms.[260] The grey area between DSD and transgender appears in the realm of gender assignment in which medical diagnoses are always recognized together with related psychosocial factors.

To sum up the discussion, in general, the Islamic perspective seemed to be placed at one end and the biological perspective is at another end. Nonetheless, they are similar, firstly, in identifying the pair of gender components. The Qurʾān mentions constantly the concept of 'pairing' for instance, "Glory to Allah, Who created in *pairs* all things that the earth produces, as well as their own (human) kind and (other) things of which they have no knowledge".[261] The pairing concept, which is the combination of opposites such as positive and negative, males and females, is proven in science.[262] It was founded by Paul Dirac, a British physicist who won the Nobel Prize in Physics in 1933.[263]

In addition, both perspectives agree on dualism of the human sex and other forms as being not the norm due to them being exception or uncommon conditions. Its rarity is proven by statistics reported by Eftihios Trakakis and others, for example, in North America 1:10,000 of life births have classical Congenital Adrenal Hyperplasia (CAH), the most common condition in intersexuality.[264] This is in line with Islamic

[260] Elizabeth M. Bucar, 'Bodies at the Margins: The Comparative Case of Transexuality', in *Religious Ethics in a Time of Globalism*, ed. by Elizabeth M. Bucar and Aaron Stalnaker (United States: Palgrave Macmillan, 2012).

[261] Translation of the Qurʾān in ʿAbdullah Yūsuf ʿAlī, *Sūrah Yā sin*, 36: 36.

[262] Bilal A. A. Ghareeb, 'Human Genetics and Islam: Scientific and Medical Aspects', *Journal of Islamic Medical Association of North America*, 43 (2011), 83- 90, p. 88.

[263] Bilal A. A. Ghareeb, p. 88; Erwin Schrödinger, *Nobelprize.Org - the Official Website of the Nobel Prize*, Paul A. M. Dirac - Biographical, 2016 (Nobel Media AB) <*http://www.nobelprize.org/nobel_prizes/physics/laureates/1933/dirac-bio.html*> [accessed 5 May 2016].

[264] Gönül Öçal, 'Current Concept in Disorders of Sexual Development', *Journal of Clinical Research in Pediatric*, 3 (2011), 105-114, p. 105; Chellapah Subashini Thambiah and others, 'Clinical Presentation of Congenital Adrenal Hyperplasia in Selected Multiethnic Paediatric Population', *Malaysia Journal of Medicine and Health Sciences*, 11 (January 2015), 77 – 83, p. 82; N. Islam, p. 196; Eftihios Trakakis and others, 'An Update to 21-Hydroxylase Deficient Congenital Adrenal Hyperplasia', *Gynecological Endocrinology*, 26 (January 2010), 63-71, p. 63.

jurisprudence which regulates general rules on frequent circumstances but deals with the exceptional conditions in its own framework. The principle of legal maxim, i.e. 'the scope of application is determined by the generality of the term used and not by the specific incident that triggered it' (*al-ʿibrah bi ʿumūm al-lafẓ lā bi khuṣūṣ al-sabab*) implying that the scope of gender refers to the general binomial sex and not divided by any specific sporadic cases.[265]

Subsequently, Islam recognizes the gender abnormality as *khunūthah* and the biological model recognizes it as DSD which was previously known as intersex or hermaphrodite. These conditions will be elaborated upon further, in order to evaluate their similarities and to identify their relationship.

3.3. Understanding the Concept of *Khunthā*: Past and Present

3.3.1. *Khunthā* in Classical Discussion

Ibn Sīnā defines *khunthā* in his medical book as,

> "a person who has no genitalia of male or female, or a person who has both types but one of them is more concealed and feebler or one of them is hidden and the other is visible and that person can urinate through one of them, not the other. And among them, both (genitalia) are equal (in functioning). And to my knowledge, some of them are active and passive but there is little verification of this knowledge. And most of them are treated by removing the feebler part and managing the injury."[266]

In the Arabic lexicon, *al-khunthā* (الخنثى) derives from the word *khanatha* (خنث), which literally means to fold and bend something, for example to fold back the mouth of a water skin (a receptacle used to hold water made of cow or sheep bladder) for drinking.[267] The concept of bending or folding depicts the transformation state from one form or shape to another, giving a vague and intricate state needing to be described.

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[265] Al-Subkī, Tāj Al-Dīn ʿAbd Al-Wahāb, *Al-Ashbāh Wa Al-Naẓā'ir (Plausible and Identical)*, vol. 2 (Beirut: Dār al-Kutub al-ʿIlmiyyah, 1991), p. 134.

[266] Al-Ḥusayn ibn ʿAli ibn Sīnā, vol. 2, p. 746.

[267] Majmaʿ al-Lughah al-ʿArabiyyah bi al-Qāhirah, *Al-Muʿjam Al-Wasīṭ (the Intermediate Dictionary)*, ed. by Ibrāhīm Muṣṭafā and others (Cairo: Dār al-Daʿwah, n.d.), p. 258.

Derived from this word are the words *khunthā* and *mukhannath* (effeminacy) in which these two forms are distinctive in social and biological perspectives but having the same root word semantically. Muḥammad Ibn Manẓūr, a lexicographer states that *khunthā* refers to a person who cannot be recognized as male or female; and the person has both criteria for men and women.[268] In *Ikhtiyār li Taʿlīl al-Mukhtār (The Efforts of Justifying the Chosen)* attributed to Ibn Mawdūd al-Mūṣilī (d. 683 AH/1284 CE), a Ḥanāfī jurist, a person is called that way due to being fractured and supple and thus lacking the character of maleness, yet having more than ordinary female characteristics.[269] Jurists of the four Sunni schools of thought (Ḥanāfī, Mālikī, Shāfiʿī and Ḥanbalī) consistently discussed the condition of *khunthā* in relation to the abnormality of an individual's sexual anatomy. This should not be confused with *mukhannath* (effeminacy), which is usually paired with suppleness (*tathannīy*) and languidness (*takassur*) in an individual's way of communication and his acts. These terms, *khunūthah* and *mukhannath*, give clear differentiation between the two conditions of biological abnormality and psychological idiosyncrasy.

Khunūthah (hermaphroditism) is understood in three different genital conditions. The first and the most mentioned condition by the jurists involves those persons who possess both male and female genitalia. Secondly, those who possess neither male nor female genitalia, but have an orifice that functions for urination purposes and are physically dissimilar with any of the two genitalia. Abū Ḥanīfah (155 AH/772 CE), the founder of the Ḥanāfī school, and his student, Abū Yūsuf (181 AH/798 CE), in contrast with other views after them, made no mention of this type and thus excluded it from the definition of *khunthā*.[270] Thirdly, the least mentioned kind is of those who possess ambiguous genitalia which do not look like male or female genitalia.[271]

The jurists introduced two types of *khunthā,* i.e. *khunthā wāḍiḥ* (discernible *khunthā*) and *khunthā ghayr wāḍiḥ* or *khunthā mushkil* (intractable *khunthā*). The classifications

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[268] Muḥammad Ibn Mukarram Ibn Manẓūr, *Lisān al-ʿArab (the Arabic Native Tounge)*, 3rd edn, vol. 8, (Beirut: Dār Ṣādir, 1414H), pp. 450-451.

[269] Ibn Mawdūd al-Mūṣilī, ʿAbd Allah ibn Maḥmūd, *Al-Ikhtiyār Li Taʿlīl Al-Mukhtār (the Efforts of Justifying the Chosen)*, vol. 3 (Cairo: Maṭbaʿah al-Ḥalabī, 1937), p. 38.

[270] Abū Ḥanīfah and Abū Yūsuf, cited in Ibn Mawdūd al-Mūṣilī, ʿAbd Allah ibn Maḥmūd, vol. 3, p. 38.

[271] ʿAlāʾ Al-Dīn, Abū Bakr Ibn Masʿūd, *Badāʾiʿ Al-Ṣanāʾiʿ fī Tartīb Al-Sharāʾiʿ* , 2nd edn, vol. 7 (Beirut: Dār al-Kutub al-ʿIlmiyyah, 1987), p. 327; ʿAbd Al-Mālik Al-Juwaynī, *Nihāyah Al-Maṭlab fī Dirāyah Al-Mazhab (Ending of the Questions in Realization of Juristic School of Thoughts)*, ed. by Maḥmūd ʿAbd Al-ʿAẓīm Al-Dayb, vol. 9 (Saudi Arabia: Dār Al-Minhāj, 2007), p. 304.

of *khunthā* depend on the level of difficulty in assigning the gender. *Khunthā wāḍiḥ* is a condition where the signs of either maleness or femaleness can be identified.[272] It is recorded in a narration that persons with this condition are entitled to inheritance as male or female based on their urine excretion. For example, *al-athar* (a narration by a Companion or a Follower recorded based on his verbal or action) related by al-Bayhaqī (d. 458 AH/1065 CE) mentions that when ʿĀlī ibn Abī Ṭālib (d. 40 AH/661 CE) was asked about a hermaphrodite, he replied, "Kindly look at the urinary orifice for there the inheritance account".[273] Legally, once the gender has been assigned, he or she will follow the rules for men or women, respectively, in relation to gender-related-juridical rules.[274] More explanation will be given on the 'narration' in subtopic 3.6. At this stage, it needs to be stated that as jurists initially focus on juridical impact, the discussions do not stress on the need for medical treatment. Therefore, in early eras, those persons were *khunthā* physically, but legally followed the rules for men or women in fulfilling their duties as Muslims.

On the other hand, if the signs to demonstrate either one of the genders are not dominant, they are identified as *khunthā mushkil.* The jurists illustrate the conditions differently through three forms of genitalia, which are: i) an orifice; ii) an ambiguous organ; and iii) two genitalia.[275] The identification of *khunthā mushkil* in the latter is disputable. Abū Ḥanīfah and al-Juwaynī (478 AH/1085 CE) assert that it refers to as early as a person urinates from both genitalia.[276] If they excrete the urine simultaneously, then it is regarded as *mushkil*. Though, Shāfiʿī scholars tend to recognize a condition as *khunthā mushkil* when there is evidence that the amount of urine excreted from both are equal. These views suggest that the monitoring can be done for infants. In contrast, Al-Ruʿīnī al-Mālikī (d. 954 AH/1547 CE) proposes, in response to Shāfiʿī, that the condition of *mushkil* is identified whenever all other signs including the phenotype of a person with two genitalia are fairly equal. This is because other physical signs may change the child's condition to *khunthā wāḍiḥ* whenever the

[272] ʿAbdullah Aḥmad Ibn Qudāmah, vol. 7, p. 207.

[273] Aḥmad Al-Ḥusayn Al-Bayḥaqī, *Sunan Al-Kubrā*, ed. by Muḥammad ʿAbd al-Qādir ʿAṭaʾ, 3rd edn, vol. 6 (Beirut: Dār al-Kutub al-ʿIlmiyyah, 2003), p. 427. No. of narration: 12513 and 12516, in chapter *Mirāth al-Khunthā* (Hermaphrodite's Inheritance).

[274] ʿAbdullah Aḥmad Ibn Qudāmah, vol. 6, p. 340.

[275] Al-Ḥaṭṭāb al-Ruʿīnī, Muḥammad ibn Muḥammad, vol. 6, p. 424; ʿAbd Al-Mālik Al-Juwaynī, vol. 9, p. 304

[276] ʿAbd Al-Mālik Al-Juwaynī, vol. 9, p. 304; ʿAlāʾ Al-Dīn, Abū Bakr Ibn Masʿūd, vol. 7, p. 327.

person reaches puberty.[277] The majority of the scholars are of this last opinion: to wait for other signs of sexual secondary characteristics such as having a beard for men or menarche for women, before making a decision about whether it is a case of *khunthā mushkil*.[278]

Mushkil does not only mean intractable, doubtful, uncertain and difficult, but it also means indeterminate. The term is therefore given to a condition that has no dominant signs, either by urine excretion rules (*ḥukm al-mabāl*) or secondary characteristics, to overweigh the feebler gender. Therefore, *khunthā mushkil* has to follow all the regulated rules, where gender is concerned.[279] Further reading on *fiqh* of *khunthā*, where specific requirements for *khunthā* in performing gender-accentuated religious obligations, is explained in Appendix C.

3.3.2. *Khunthā* in Contemporary Discussion

Most available English literature on *khunthā* translate it as hermaphrodites, either using the term throughout the article or only for defining purposes.[280] Zaliha Tak writes on *khunthā* in the Malay language and attributes the term in English as hermaphrodites. There is nothing wrong with the definition as it is clearly translated so. For example, in *Al-Mawrid al-Wasīṭ*, an Arabic-English dictionary, it is described as being hermaphrodite, bisexual, gynandromorphy and intersex.[281] Likewise, *khunsa* in the Malay language (which is adapted from Arabic) and *banci* in the Indonesian

[277] ʿAbd Al-Mālik Al-Juwaynī, vol. 6, p. 424.
[278] ʿAbdullah Aḥmad Ibn Qudāmah, vol. 6, p. 336.
[279] ʿAbdullah Aḥmad Ibn Qudāmah, vol. 6, p. 258.
[280] Abdulaziz Abdulhussein Sachedina, *Islamic Biomedical Ethics Principles and Application,* (Oxford; New York: Oxford University Press, 2009), p. 193; Sayed S. Haneef, 'Sex Reassignment in Islamic Law: The Dilemma in Transsexuals.', *International Journal of Business, Humanities and Technology,* 1 (2011), p. 101; Paula Sanders, 'Gendering the Ungendered Body: Hermaphrodites in Medieval Islamic Law', in *Women in Middle Eastern History - Shifting Boundaries in Sex and Gender*, ed. by Nikki R. Keddie and Beth Baron (New Haven: Yale University Press, 1991), p. 1; Zaliha Tak, *Khuntha Dan Mukhannath Menurut Perspektif Islam (Khuntha and Transgender from the Islamic Perspective)* (Kuala Lumpur: Jabatan Kemajuan Islam Malaysia, 1998), p. 12; Everett K. Rowson, 'The Effeminates of Early Medina', *Journal of American Oriental Society,* 111 (October - December 1991), 673. Mohammad Hashim Kamali, 'Transgender, from Islam's Perspective', *New Straits Times,* 29 December 2009, para 1; Sayed S. Haneef and Mahmood Zuhdi Abdul Majid, 'Medical Management of Infant Intersex: The Juridico-Ethical Dilemma of Contemporary Islamic Legal Response', *Zygon: Journal of Religion & Science,* 50 (December 2015), 809 – 829, p. 811.
[281] Rūḥī Al-Baʿalbakī, *Al-Mawrid Al-Wasīṭ (A Concise Arabic-English Dictionary)* (Beirut: Dār al-ʿIlm li al-Malāyīn, 1991), p. 334.

language also have been translated as hermaphrodites.[282] Nevertheless, this term is connected to medical expressions leading to another perspective of *khunthā* as will be elaborated further, later, when analysing the relationship between *khunthā* and DSD.

Based on contemporary literature, especially in Malaysia and Indonesia, there is a misconception about what is *khunthā wāḍiḥ* and *khunthā mushkil. Khunthā* "is known and often perceived by mistake as persons with double genitals".[283] In an interview conducted, Roziana Ariffin, a Consultant Clinical Cytogeniticist and Head of Genetics Lab, Kuala Lumpur General Hospital simply defined *khunthā* as 'doubled' or 'doubling'.[284] Presumably, the error is based on the literal meaning of *wāḍiḥ* and *mushkil*. *Wāḍiḥ* is translated as clear and has been associated with two unambiguous genitals. On the other hand, *mushkil* is translated as vague and has been associated with ambiguous genitalia, regardless whether the person can belong to a male or female category at any given time. However, as mentioned before, the categorization is not based on the genital form, rather it is based on the difficulty of assigning the gender. Therefore, surgery for *khunthā mushkil,* as will be described further in Chapter 5 (subtopic 5.5), is regarded as a futile act based on the fatwa published by the General Presidency of Scholarly Research and Iftāʾ of Saudi Arabia, in contrast with a fatwa produced in 1989 by the Fatwa Committee of the National Council of Islamic Affairs, Malaysia which allows sex assignment surgery for *khunthā mushkil*.[285]

Presently, people with *khunthā wāḍiḥ* are not left untreated if medical treatment is sought. It becomes a temporary condition beginning with case identification until the gender is ascertained and ending with medical action. Afterwards, such persons can be recognised as male or female, physically and legally, while the *khunthā mushkil* are

[282] Institute of Language and Literature Malaysia, *Pusat Rujukan Persuratan Melayu*, Kamus Bahasa Melayu (Malay Dictionary), (Dewan Bahasa dan Pustaka, 2015), *in Kedi* <http://prpm.dbp.gov.my/Search.aspx?k=kedi> [accessed 12 November 2015]; *Kamus.Net*, (2016) <*http://www.kamus.net/*> [accessed 12 May 2016].

[283] Annastasia Ediati, 'Disorders of Sex Development in Indonesia: The Course of Psychological Development in Late Identified Patients' (PhD, Diponegoro University, Semarang, Indonesia, 2014), p. 18.

[284] Roziana Ariffin, *Email to Taqwa Zabidi*, 9 September 2016.

[285] General Presidency of Scholarly Research and Ifta, *Fatāwā Al-Lujnah Al-Dāʾimah (Fatwa of General Presidency)*, ed. by Aḥmad ʿAbd Al-Razāq Al-Duwaish, vol. 25 (Riyadh: Riʾāsah Idārah al-Buḥūth al-ʿIlmiyyah wa al-Iftāʾ, n.d.), p. 49; Department of Islamic Development Malaysia, *Decision of the Fatwa Committee of the National Council for Islamic Religious Affairs Malaysia* (Putrajaya: Department of Islamic Development Malaysia, 2010). Further discussion on this aspect will be elaborated in Chapter 5 pertaining to the treatment.

those who, at the end of the day, cannot be assigned any gender.[286] With the insight of today's biomedical technology, less people are recognized as *khunthā mushkil* because their issues can be resolved medically. Though, they will remain in this category, rendering themselves as belonging nowhere, both physically and legally, if the doctors fail to identify their gender.[287] Thus, they are obliged to remain with the legal rulings of religious obligations for *khunthā* or 'juristic theory of hermaphroditism', as coined by Sayed Sikandar Shah Haneef.[288] Further reading on the rulings can be referred to Appendix C.

The classical delineation is remained unchanged, until biomedical studies appeared with a large number of studies on the abnormality of human biological development. In 1993, Zuhayr Aḥmad Al-Sibāʿī and Muḥammad ʿAlī al-Barr come out with new perspectives on *khunthā* and associated it with biomedical findings. They assert that the classical juristic approach is at variance with the medical perspective on *khunthā*.[289]

The awareness of the human biological development expanded and is now noticed in some of the literature on *khunthā*. Nevertheless, the relationship between the Islamic and biomedical framework is not altogether clear. Tak, for example, lies on the classical side and asserts that the biological processes including the chromosomes and hormones are merely the scientific explanation of abnormalities.[290] In 2008, an online fatwa supervised by Shaykh Muḥammad Ṣāliḥ al-Munajjid, a scholar from Saudi

[286] Sayyid Sābiq, *Fiqh Al-Sunnah*, vol. 3 (Beirut: Dār al-Kitāb al-ʿArabiy, 1987), p. 485.

[287] Muṣṭafā Al-Khin, Muṣṭafā Al-Bughā and ʿAlī Al-Sharbajī, *Al-Fiqh Al-Manhajī ʿAla Mazhab Al-Shāfiʿī (Juristic Approach of Shāfiʿī School of Thought)*, 4th edn, vol. 5 (Damascus: Dār al-Qalam, 1992), p. 128.

[288] Al-Suyūṭī, Jalāl al-Dīn ʿAbd al-Raḥman Ibn Abū Bakr, *Al-Ashbāh Wa Al-Naẓāʾir fī Qawāʿid Wa Furūʿ Fiqh Al-Shāfiʿiyyah (Plausible and Identical in Methodologies and their Branches of Shāfiʿī School of Thought)*, 1st edn, vol. 1 (Beirut: Dar al-Kutub al-`Ilmiyyah, 2001), p. 52; Sayed S. Haneef and Mahmood Zuhdi Abdul Majid, p. 811. Haneef is a Professor of Islamic Jurisprudence at International Islamic University of Malaysia.

[289] Zuhayr Aḥmad Al-Sibāʿī and Muḥammad ʿAli Al-Barr, *Al-Ṭabīb Adabuh Wa Fiqhuh (Ethics of Physician and its Jurisprudence)* (Damascus: Dār al-Qalam, 1993), p. 313. The article was initially presented by Muḥammad ʿAlī al-Bar, a consultant of Islamic Medical Studies at Medical Research Centre of al-Malik Fahd, in the Conference of Majmaʿ al-Fiqh al-Islāmī (Islamic Fiqh Academy) on 1 Zu al-Qaʿidah 1412 (4 May 1992). See also *Mushkilah al-Khunthā Bayn al-Ṭibb wa al-Fiqh* (Issues on Khuntha Between Medicine and Islamic Jurisprudence), *Majallah Majmaʿ al-Fiqh al-Islāmī bi Rābiṭah al-ʿĀlam al-Islāmī*, al-Sanah al-Rābiʿah, no. 6, 2nd edn., 2005, pp. 345 – 366.

[290] Zaliha Tak, p. 15.

Arabia, explained *khunthā* by referring to the established classical concept.[291] Later, in 2012, in replying to a question regarding the condition of a child who had both testes (normally existing in a male) and female external genitalia, he mentioned that this is a part of *khunthā mushkil* and the chromosomal factor should be taken into account in assigning the gender.[292]

Coming back to al-Sibāʿī's and al-Barr's opinion, they did indeed acknowledge the *ijtihād* of the jurists but they were then in an era predating the advances of biomedical technology. Whilst the jurists emphasize on urine excretion (*al-mabāl*); physicians point out the role of chromosomes and gonads, as will be clarified further in the next topic. Al-Sibāʿī and al-Barr do not criticise the elements within the early definition but it is understood that, they are of the opinion that by limiting the scope to the jurists' decision, it may lead to poor gender assignment for the patient. Therefore, they, as well as Aḥmad Muḥammad Kanʿān, argue that this kind of case should be handed over to the physicians to deal with, for medical policies do not only look at external genitalia, but also the chromosomal and gonadal factors.[293]

3.4. Disorders of Sex Development (DSD) and Its Classifications

DSD is a contemporary term for hermaphroditism or intersex. History records that the word hermaphrodite was introduced to the English language via Latin from the Greek language in 1398. It is believed that it started from the tale of Hermaphroditus, who was the son of Hermes and Aphrodite. The gods joined the body of Hermaphroditus with the water-nymph Salmacis, who was falling in love with him, as an answer to Salmacis' prayer. Therefore, Hermaphroditus was a combination of being male and

[291] Ṣāliḥ Al-Munajjid, *Al-Islām Suʾāl Wa Jawāb (Islam Question and Answer),* [Online] Available at <https://islamqa.info/ar/answers/114670/حكم-زواج-الخنثى-و-العاجز-جنسيا-والفرق-بينهما> (2016) [accessed 12 May 2016]. Fatwa No.: 114670 '*Ḥukm Zawāj al-Khuntha wa al-ʿĀjiz Jinsiyya wa al-Farq Baynahuma* (Rulings on Marriage of a Hermaphrodite and a Person with a Sexual Disorder and the Differences between Them).'

[292] Ṣāliḥ Al-Munajjid, [Online] Available at < https://islamqa.info/ar/answers/182253/حكم ازالة-الاعضاء-الذكرية-من-الخنثى-المحكوم-بانها-انثى> [accessed 12 May 2016]. Fatwa No.: 182253 '*Ḥukm Izālah al-Aʿḍāʾ al-Zakariyyah min al-Khunthā al-Maḥkūm biʾAnnahaʾUnthā* (Rulings on Removing Male Organs from a Person Recognised as Female).'

[293] Zuhayr Aḥmad Al-Sibāʿī and Muḥammad ʿAli Al-Barr, p. 323-324; Aḥmad Muḥammad Kanʿān, *Al-Mawsūʿah Al-Ṭibbiyyah Al-Fiqhiyyah (the Encyclopaedia of Medical Islamic Jurisprudence)*, 2nd edn (Beirut: Dār al-Nafāʾis, 2006), p. 440.

female. The word then, was attributed to an animal that is comprised of male and female gender but is always imperfect.[294]

It is well understood that hermaphroditism is a common state of being for certain plants and animals based on scientific research. In the 18th century, the term was adapted for a human being's condition, but as a monstrous malformation state.[295] The term of hermaphrodites was used in medical settings to indicate at least three types, namely true hermaphrodites (having both testicular and ovarian tissue with or without ambiguous genitalia), male pseudo-hermaphrodites (having testes with ambiguous genitalia) and female pseudo-hermaphrodites (having ovaries with ambiguous genitalia). The origin of the terms were somehow turned into becoming derogatory and mythological terms which were seemed as humiliating the patients and their families.[296]

The term hermaphrodites was gradually less used, and the new term coined by Richard Goldsmith in 1917, i.e. intersex, was and is still used by physicians instead.[297] The US National Library of Medicine defines intersex as 'a group of conditions where there exists a discrepancy between the external genitals and the internal genitals (the testes and ovaries)'.[298] In other words, the Intersex Society of North America (ISNA) refers to it as 'a variety of conditions in which a person is born with a reproductive or sexual anatomy that does not seem to fit the typical definitions of female and male'.[299] Giving a clearer definition, Ieuan A. Hughes explains that intersex in a clinical scenario refers to an infant born with external genitalia sufficiently ambiguous that sex assignment is not possible'.[300]

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[294] Jane Seymour, 'Hermaphrodite', *The Lancet*, 377 (2011), 547.

[295] Jane Seymour, p. 547.

[296] Elizabeth Reis, 'Divergence Or Disorder?: The Politics of Naming Intersex', *Perspectives in Biology and Medicine*, 50 (2007), 535 – 543, p. 536; I. A. Hughes, 'Disorder of Sex Development: A New Definition and Classification', *Best Practice & Research Clinical Endocrinology & Metabolism*, 22 (February 2008), 119 – 134, p. 120.

[297] Elizabeth Reis, p. 536.

[298] National Institute of the Health, *Medline Plus*, Intersex (United States: U.S National Library of Medicine, 3 May 2016), para. 1, [Online] Available at <https://www.nlm.nih.gov/medlineplus/ency/article/001669.htm> [accessed 24 May 2016].

[299] Intersex Society of North America, *Intersex Society of North America*, [Online] Availabel at <isna.org>, 2016 (North America: Intersex Society of North America, 2008), para 1 of 10, [accessed 24 May 2016].

[300] I. A. Hughes, 2008, p. 120.

There are a few criticisms on the use of this term that urge the physicians towards rethinking about it. Despite parents' uneasiness about the condition of their children being in between male or female, the definition of intersex itself is restricted as there is exclusion of anomalous conditions which do not have ambiguous genitalia.[301] Consequently, the European Society for Paediatric Endocrinology and the Lawson Wilkins Paediatric Endocrine Society came to a consensus on to replace the term with the umbrella term, Disorders of Sex Development.[302] This consensus is known as the Chicago Consensus. The consensus was achieved through a conference that attended by endocrinologists, surgeons, geneticists, psychologists and patient advocacy group members at the global level.[303]

DSD is defined as 'a congenital condition in which the development of chromosomal, gonadal or anatomical sex is atypical'.[304] This new nomenclature implies, firstly, that all other conditions which are identified as causes of precocious or delayed puberty are excluded by the word 'congenital'. The second implication is that there is a mismatch between chromosomes, gonad and external genitalia. The thirdly is that DSD embraces almost all conditions of congenital sexual anomalies, with or without ambiguous genitalia. Figure 4 highlights elements that can contribute to the DSD, where an atypical condition is concerned.

[301] Elizabeth Reis, p. 537; I. A. Hughes, 2008, p. 120.
[302] I. A. Hughes, 2008, p. 120.
[303] I. A. Hughes, 2008, p. 120.
[304] I. A. Hughes, 2008, p. 120.

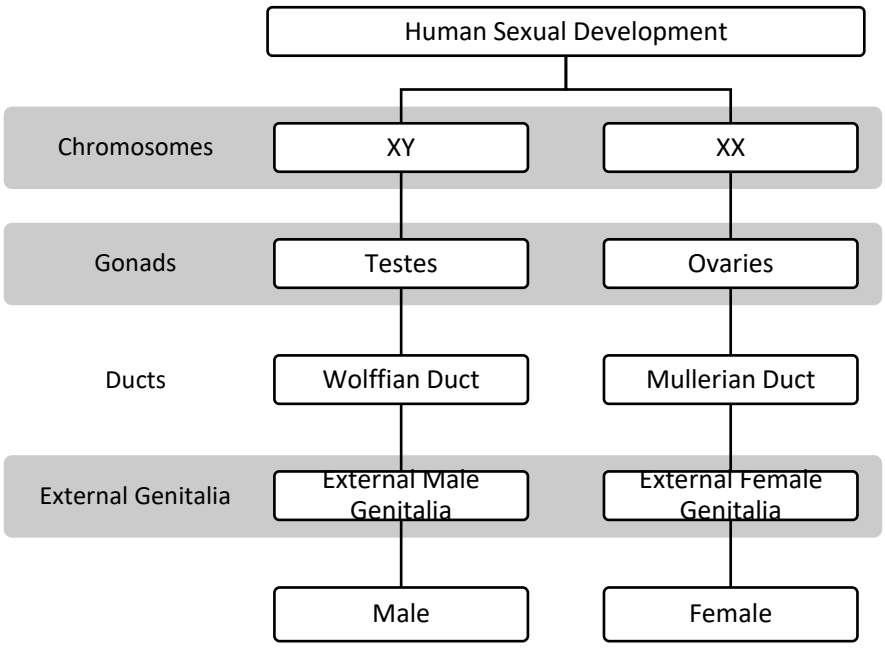

Figure 4: The stages at Which Atypical Situations Can Arise in Human Sexual Development

With the changing of the generic name, nomenclatures related to pseudo-hermaphroditism were also replaced by chromosomal terms, acknowledging the karyotype analysis that is undertaken in most cases of DSD.[305] There are three main diagnostic categories of DSD, namely 46,XY DSD (previously known as male pseudo-hermaphrodite), 46,XX DSD (previously known as female pseudo-hermaphrodite) and sex chromosome DSD as shown in Table 2.[306] Within each category there are various conditions that are affected by several causes along the process of, either, sex determination or three types of sex differentiation as have been stated recently.

[305] Karyotype refers to the characterization of the chromosomal complement of an individual or a species including number, form and size of the chromosomes. See *The American Heritage® Medical Dictionary,* <http://medical-dictionary.thefreedictionary.com/karyotypic>, Karyotypic, 2007 (n.d.) [accessed 24 May 2016]. I. A. Hughes, 2008, p. 121.

[306] I. A. Hughes, 2008, p. 121. Table 1 is adapted to show the connection between three categories of DSD and forms of genital ambiguity as will be discussed further, later.

Table 2: Classification of DSD and the Condition of External Genitalia

Categories	1. Sex Chromosome DSD				2. 46,XX DSD	3. 46,XY DSD
	a. 46,XX/46,XY	**b. 45,X/46,XY**	**c. 47,XXY**	**d. 45,X**		
Causes	Ovotesticular DSD	Mixed Gonadal	Klinefelter Syndrome & variants	Turner's Syndrome & variants	- Congenital Adrenal Hyperplasia - Excess Maternal Androgen Production - Ovotesticular DSD	- Partial Gonadal Dysgenesis - Deficiency of Testosterone Biosynthesis - 5α-reductase 2 - Partial Androgen Insensitivity Syndrome - Ovotesticular DSD
External genitalia	Both male and female genitalia	Ambiguous genitalia	Normal male genitalia	Normal female genitalia (with rare cases of ambiguous genitalia)	Ambiguous genitalia with variable degrees of virilisation.	Ambiguous genitalia with incomplete virilisation.

The first category indicates that the physical disturbance starts with sex chromosome anomalies which can happen either by a mosaicism of chromosomes (as shown as 1a and 1b), or by gaining (trisomy) or losing a pair of sex chromosomes (monosomy) (as shown as 1c and 1d respectively).[307] In the mosaicism of chromosome, one may carry two cell lines as follows:

a. 46,XX/46,XY (1a). The karyotype pattern is also known as chimerism whereby a person has two complete genomes (sets of DNA) in their body. The cause is identified as Ovotesticular DSD or previously known as true hermaphrodite can happen with sex chromosome anomalies, i.e. 46,XX/46,XY although it also can happen with 46,XX and 46,XY. A person who is having this type of DSD may have both ovarian and testicular tissues and a variable degree of ambiguous genitalia or have both male and female genitalia.[308]

[307] N. Islam, p. 196, Aḥmad Muḥammad Kanʿān, p. 438. Mosaicism of chromosome refers to 'an individual or cell cultures having two or more cell lines that are karyotypically or genotypically distinct but are derived from a single zygote'. See 'Dorland's Medical Dictionary for Health Consumers', (2007) <http://medical-dictionary.thefreedictionary.com/chromosome+mosaicism> [accessed 27 May 2016].

[308] Leonard Sax, p. 174.

b. 45,X/46,XY (1b). This condition is identified due to mixed gonadal dysgenesis.[309] In this condition, a person may have testis and streak gonad (undeveloped gonad) with a variable degree of ambiguous genitalia or female external genitalia.[310] One of the cases presented in Department of Islamic Development Malaysia (JAKIM) was of this type. The person was brought up as female due to identification of female-genital alike at birth, but it happened to develop as male genitalia at later age.[311]

In the third type of Sex Chromosome DSD category is shown that one may carry an additional Y chromosome, resulting in 47,XXY which is known as Klinefelter syndrome (1c).[312] This condition occurs once in about every 400 live male births. The patients diagnosed with this syndrome is associated with infertility and the physical changes are very subtle. The fourth type of Sex Chromosome DSD is that one can lose another pair of sex chromosomes, marked as XO. This is the only monosomy chromosome yet recognised. The caused is known as Turner's syndrome and identified as 45,XO (1d). The patients are female in appearance, although they lack of many secondary sexual characteristics.[313] Generally, these conditions are not associated with genital ambiguity and should be regarded as chromosomal aberration, unless the following very few cases that have been reported recently are taken into account.[314] Undeveloped genitalia of Turner's syndrome and genital anomalies in Klinefelter syndrome were reported by Suresh Vaddadi and others and Lee Y.S. and others.[315]

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[309] N. Islam, p. 198; I. A. Hughes, p. 122.

[310] Dysgenesis refers to defective or abnormal development of an organ, especially the gonads. See more in *The American Heritage® Medical Dictionary*.

[311] Taqwa Zabidi, *Hukum Penetapan Jantina Bagi Pesakit Mixed Karyotype (Rulings on Gender Assignment for Patient with Mixed Karyotype)*, Kertas Kerja Mesyuarat Panel Pakar Syariah Jabatan Kemajuan Islam Malaysia *(Paperwork of Shariah Expert Panel Meeting, Department of Islamic Development Malaysia*), vol. 86 (Putrajaya: 2014), 1 – 36, p. 10.

[312] N. Islam, p. 196; Aḥmad Muḥammad Kanʿān, p. 438. The trisomy chromosome, where a person may carry additional X chromosome, resulting in XXX or sometimes XXXX chromosome is not indicated in the table as the patients are often fertile, producing normal offspring and difficult to diagnose clinically.

[313] N. Islam, p. 197; Aḥmad Muḥammad Kanʿān, p. 438. The monosomy chromosome is also identified in YO chromosome. However, it is apparently incompatible with life.

[314] I. A. Hughes, 2008, p. 121; Govind B. Chavhan and others, p. 1893; Ian A. Aaronson and Alistair J. Aaronson, 'How should we Classify Intersex Disorders?', *Journal of Pediatric Urology*, 6 (2010), 433 – 436, p. 446; Pierre Mouriquand and others, 'An ESPU/SPU Standpoint on the Surgical Management of DSD', *Journal of Pediatric Urology*, 10 (2014), 8 – 10, p. 8.

[315] Suresh Vaddadi and others, 'A Rare Case of Turner's Syndrome Presenting with Mullerian Agenesis', *Journal of Human Reproductive Science*, 6 (Oct - Dec 2013), 277-279; Y. S. Lee and others, 'Genital Anomalies in Klinefelter's Syndrome', *Hormone Research in Paediatric*, 68 (2007), 150-155.

The most common condition in category 2, '46,XX DSD', is illustrated in an individual having 46,XX sex chromosomes (which indicate a female) with normal ovaries and internal female organs but having ambiguous genitalia of variable degrees. Congenital Adrenal Hyperplasia (CAH) is identified as the majority cases of 46,XX DSD and even the most common group causing ambiguous genitalia in female newborns. The high prevalence also has been reported in South East Asia such as in Malaysia, Thailand and Indonesia.[316] Whilst, category 3, '46,XY DSD', is generally identified as having male genotype, i.e. testes but with a variable degree of undervirilisation of the external genitalia.[317] These two categories are identified due to gonadal histology, rather than chromosome anomaly as occurred in category 1.

The karyotypic based categorization of chromosomes sometimes leads to overlapping conditions from endocrinology perspectives, as we have seen in the case of ovotesticular DSD.[318] It is quite difficult to ascertain genital ambiguity based on these categorizations because this umbrella term includes both cases of ambiguous and unambiguous genitalia.[319] Table 1 shows the classification of DSD and the condition of external genitalia.

Genital ambiguity is the main concern in this chapter. It is essential to have clarity in order to evaluate the relationship of *khunthā* and DSD. The condition is usually identified at birth for newborns whenever the appearance of external genitalia does not look like typical male or female genitalia.[320] The Prader scale is used to assess the extent of the ambiguity from 0 for the typical female genitalia to 6 for the typical male genitalia or based on new classifications adapted by Richard C. Rink and others, from 0 for normal genitalia to 6 for deviations that do not fit any category.[321] The conditions

[316] Mark Woodward and Nitin Patwardhan, 'Disorders of Sex Development', *Paediatric Surgery II*, 28 (2010), 396 – 401, p. 400; Loo L. Wu and others, 'High Frequency of Classical 21Hydroxylase Deficiency (CAH) in Malaysia', *Pediatric Research,* 36 (July 1994), 22A; S. Nimkam and others, 'Ambiguous Genitalia: An Overview of 22 Years' Experience and the Diagnostic Approach in the Paediatric Department, Siriraj Hospital', *Journal of Medical Association of Thailand,* 85 (August 2002), S496-505; A. Zulfa Juniarto and others, 'Application of the New Classification on Patients with a Disorder of Sex Development in Indonesia', *International Journal of Paediatric Endocrinology,* (2012).

[317] Govind B. Chavhan and others, 'Imaging of Ambigous Genitalia: Classification and Diagnostic Approach', *Radiographics,* 28 (November - December 2008), 1893.

[318] Ian A. Aaronson and Alistair J. Aaronson, p. 434.

[319] I. A. Hughes, 2008, p. 121; Govind B. Chavhan and others, p. 1893.

[320] Govind B. Chavhan and others, p. 1893.

[321] Richard C. Rink, Mark C. Adams and Rosalia Misseri, 'A New Classification for Genital Ambiguity and Urogenital Sinus Anomalies', *BJU International,* 95 (2005), 638 – 642, p. 641.

of ambiguous genitalia related to DSD must be understood and should not, in any circumstances be confused with variant forms of genitalia which have no or little health risks.

For the purpose of this research, the reference of genital ambiguity's scale will be made according to the Prader score. Level 1 of the Prader scale shows a condition involving clitoral enlargement or hypertrophy. In level 2, clitoral hypertrophy occurs with urethral and vaginal orifices present but located very near each other. The third level indicates clitoral hypertrophy with a single urogenital (urinary and genital sinus) orifice and fusion of labia majora (major lips: fleshy folds of tissue that extend down from the mons pubis and bordering the vulva and vaginal opening). Level 4 is early signs of the formation male genitalia. A penile clitoris occurs with perineoscrotal hypospadias and complete fusion of the labia majora.[322] The last condition on the scale of genital ambiguity occurs when there is completely formed male genitalia without any palpable (tangible) testes.[323]

3.5. *Khunūthah* and DSD: Similar but not Exactly Identical

Khunūthah and DSD have some similarities and differences. Generally, both Islamic and medical perspectives argue for subsuming these conditions under the dualism of male and female gender. Semantically, the term hermaphrodite which is the translation of *khunthā* was also the former term used for DSD, thereby referring the two perspectives as one. This can be seen from the limited literature describing DSD from Islamic perspectives. For instance, a piece of medical literature authored by Mohd Salim Mohamed and Siti Nurani Mohd Noor explains *khunthā* as 'the Islamic term for newborns with DSD'.[324] Another article written by Islamic experts, Sayed Sikandar Haneef and Mahmood Zuhdi Abd Majid states that 'Islamic law regards such an

[322] Hypospadias is a birth defect that usually occurs to a male's urethra, where the urinary opening is not at the head of the penis. Perineoscrotal hypospadias is a severe hypospadiac penis where the opening is at the perineum and forms vagina-like genitalia and masculinizes at puberty. See *Segen's Medical Dictionary,* <*http://medical-dictionary.thefreedictionary.com/pseudovaginal+perineoscrotal+hypospadias*>, Pseudovaginal Perineoscrotal Hypospadias, (n.d.) [accessed 8 July 2016].

[323] Nasir A. M. Al-Jurayyan, p. 288

[324] Mohd Salim Mohamed and Siti Nurani Mohd Noor, 'Islamic Bioethical Deliberation on the Issue of Newborns with Disorders of Sex Development', *Science and Engineering Ethics,* 20 (25 Mar 2014), 429 – 440, p. 435.

anomaly as a birth defect while medical science terms it as a disorder of sex development (DSD) popularly known as an intersex condition'.[325]

Only one piece of medical literature is still using the term *khunthā,* because the authors are looking for an 'update of the Islamic definitions to align with modern understanding of the anatomy'.[326] Careful use of the terminology is important because it has legal impacts for *khunthā,* for example in performing religious obligations and the rights to undergo sex change, if required.

The more clearly common element linking *khunūthah* and DSD is the ambiguous condition of the genitalia. However, there are slightly different forms of the ambiguity. Islamic jurists say that normal genitalia in their uncommon presence, (which is the combination of two genitals in a body) is a sign of *khunthā* hence excluding any single normal genitalia from the definition of *khunthā*. On the other hand, DSD embraces single normal genitalia with the disjunction of chromosomal and/or gonadal factors. This marks the difference between *khunthā* and DSD. Haneef argues that,

> "DSD conditions generally cannot be in concordance with what Muslim jurists thought of [as] *khunthā*. The majority of jurists classify a baby born with external genital abnormality as determinate or indeterminate based on matters associated with its urination. At puberty again the sexual function of such an individual's genitals was the deciding factors to the vast majority *except [for] some dissenting views which pointed to behavioural traits which may lend support to [the] recognition of DSD today*."[327]

The presence of uncommon urine excretion becomes a '*ratio legis*' of Islamic law in this situation.[328] In this aspect, we should consider the discussion of the experts of the principles of Islamic jurisprudence on *ʿillah*. *ʿIllah* or *manāṭ al-ḥukm* i.e. the cause of the ruling should be clearly understood before applying any ruling. The element of *ʿillah* itself should fulfil four attributes namely: being appropriate (*munāsib*), visible (*ẓuhr*), constant (*munḍabiṭ*) and transferable (*mutaʿaddiy*).[329] As Jasser Auda, a

[325] Sayed S. Haneef and Mahmood Zuhdi Abdul Majid, p. 809.

[326] Ani Amelia Zainuddin and Zaleha Abdullah Mahdy, 'The Islamic Perspectives of Gender-Related Issues in the Management of Patients with Disorders of Sex Development', *Archives of Sexual Behavior*, (21 April 2016), 1 – 8, p. 3.

[327] Sayed S. Haneef, *Email to Taqwa Zabidi* (28 May 2016).

[328] Mohd Kashim, Mohd Izhar Ariff, *Telephone Conversation with Taqwa Zabidi*, (13 January 2016); Sayed S. Haneef, *Email to Taqwa Zabidi*.

[329] Wahbah Al-Zuḥaylī, *Al-Wajīz fī ʾUṣūl Al-Fiqh (A Compendium of Principles of Islamic Jurisprudence)* (Beirut: Dār al-Fikr, 1995), pp. 72 – 75.

Founding Director of Al-Maqasid Research Centre, United Kingdom argues, the question analysis of *ʿillah* needs to be referred to the specialists in related fields and not to jurists.[330] This justifies the need to amalgamate the discussion of *khunthā* and DSD. Based on numerous case reports of DSD, it could be identified in the prevalence of cases with or without genital ambiguity.

Hence, by considering biological characteristics of the genitalia, it is argued that ambiguous urine excretion is the *ʿillah,* as it is 'appropriate' (*munāsib*) enough to identify a person as *khunthā* in which its presence can exclude the person from common legal juridical rules typically associated with being either male or female. It is also 'visible' that an expert can examine its form based on various types of genital ambiguity as the manifestation of urine excretion. The condition within its variable degrees of ambiguity, is 'constant' regardless of taking into account of individuals, eras, geographical locations and circumstance. For example, affected people in the West may have the same condition as affected people in Asia. Lastly, the condition can be 'applied' to various cases, presenting variable degrees of ambiguity. It is not unique for very specific cases only.

Evidently, not all DSD can be referred to as *khunthā* but *khunthā* can be identified as a person with Disorders of Sex Development (DSD) such as in Figure 5. Any DSD types that retain normal male and female genitals are not regarded as *khunūthah* just as they are excluded from intersex. Contemporary Islamic scholars and a medical practitioner in Malaysia who have been interviewed are also of this opinion, thereby ensuring there would be a very clear differentiation from the generally-accepted transgender condition.[331]

Therefore, in the presence of this *ʿillah*, the related rulings are applicable. Whilst, the rulings are absent in the absence of *ʿillah*. This refers to a legal maxim, *al-ḥukm yadūr maʿ ʿillatih wujūda wa ʿadama* (a ruling is considered based on presence of the cause

[330] Jasser Auda, *Maqāṣid Al-Sharīʿah as Philosophy of Islamic Law - A System Approach*, Special edn (Selangor: Islamic Book Trust, 2010), p. 118.

[331] Islamic Expert 1, *Conversation with Taqwa Zabidi* (27 August 2015); Islamic Expert 2, *Telephone Conversation with Taqwa Zabidi*, (21 January 2016); Mohd Kashim, Mohd Izhar Ariff, *Telephone Conversation with Taqwa Zabidi*, Abdul Rahman Osman, *Telephone Communication with Taqwa Zabidi*, (27 February 2016); Sayed S. Haneef *Email to Taqwa Zabidi*: Ani Amelia Zainuddin, *Skype Conversation with Taqwa Zabidi* (20 July 2016).

or its absence).[332] In the event of non-existence of the ambiguous genitalia, the ruling of *khunthā* cannot be applied.

Common examples of DSD cases with normal genitalia are Klinefelter and Turner syndromes unless for very rare cases reported with abnormal genitalia.[333] Some of Congenital Adrenal Hyperplasia (CAH) cases are not intersex manifestations and the Complete Androgen Insensitivity Syndrome (CAIS) is patently not an intersex condition.[334]

Other types of DSD with genital ambiguity entail the condition of *khunthā*. Most of them are regarded as *khunthā wāḍiḥ* in which the 'correct' or the dominant gender can be identified. Firstly, there is the extremely rare condition, where it involves having dual genitals known as true hermaphroditism or one of the manifestations of ovotesticular DSD in 46,XX/46,XY DSD.[335] Based on urine excretion rules, it becomes effortless to assign the 'correct' gender, and this state precisely refers to *khunthā wāḍiḥ*.[336] Although it is argued that ovotesticular DSD is not an intersex condition due to its non-disjunction between phenotypic sex and genotypic sex, the overarching DSD classifications embrace this condition due to its karyotypic abnormality.[337] This type is also not included in the Prader scale of genital malformation.

The second type of ambiguity refers to variable degrees of virilisation of the Prader scale as aforementioned. Level 3 of this scale indicates on orifice type that has been mentioned by Muslim jurists. Whilst other levels on the Prader scale refer to genitals that do not look like male nor female genitals. When the identification of the gender is

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[332] Ṣāliḥ Ibn Muḥammad Al-Qahṭānī, *Majmūʿah Al-Fawāʾid Al-Bahiyyah fī Manẓūmah Al-Ḳawāʿid Al-Fiqhiyyah (Collections of the Glorious Benefit in Arranging Legal Maxims)*, ed. by Mutʿab Ibn Masʿūd Al-Jaʿīd (Saudi Arabia: Dār al-Ṣamīʿī, 2000), p. 112. This concept has been introduced by earlier classical scholars such as Muḥammad Ibn Aḥmad Al-Sarakhsī, *Uṣūl Al-Sarakhsī (Basis of Al-Sarakhsī)*, (Beirut: Dār al-Maʿrifah, n.d.), p. 181.

[333] Aḥmad Muḥammad Kanʿān, p. 322; Leonard Sax, p. 176; Pierre Mouriquand and others, p. 8.

[334] I. A. Hughes, 2008, p. 120. Androgen is one of a group of steroid hormones, including testosterone and dihydrotestosterone, that stimulate the development of male sex organs and male secondary sexual characteristics. The definition is based on *Concise Medical Dictionary*, 8th edn (Oxford: Oxford University Press, 2010). [Online] Available at <https://www-oxfordreference-com.ezproxy.uwtsd.ac.uk/view/10.1093/acref/9780199557141.001.0001/acref-9780199557141> [accessed 15 November 2016].

[335] Michelle Ceci and others, 'A Case of True Hermaphroditism Presenting as Testicular Tumour', *Hindawi Publishing Corporation*, (2015), 1.

[336] Aḥmad Muḥammad Kanʿān, p. 313.

[337] Leonard Sax, p. 175.

not straight forward, there are other signs that can be referred to, including chromosomes, gonads and secondary sexual characteristics. More details will be explained further in discussing the issue of gender assignment in Chapter 4. Yet, supported with those signs, almost all the DSD cases are discernible and determinate; *wāḍiḥ*. As the technology develops and the knowledge expands, it will be possible to ascertain the gender of most *khunthā* cases, leaving only the very subtle abnormalities beyond the capability of doctors. Those unrecognisable cases will retain the description of *khunthā mushkil* (intractable).

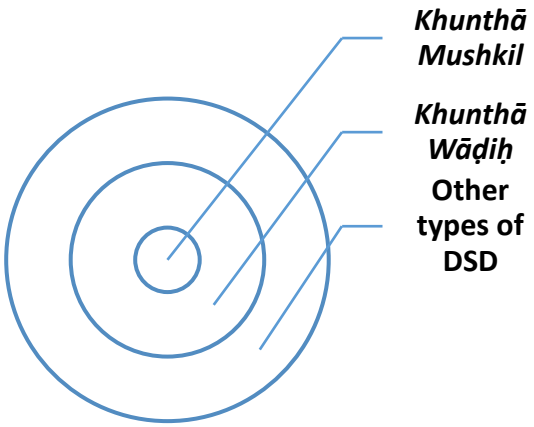

Figure 5: Relationship of Disorders of Sex Development and Khunthā

Suggesting identification of types of *khunthā* by DSD classifications is insubstantial and prone to changes for two reasons. Firstly, as we have seen, the progressive biotechnology findings and social development leads to the dynamism of the nomenclature and its categories. Although it is reported that there is consensus agreement on current terms and broad support by parents and health professionals, there are recommendations for retaining the term of intersex or other terms such as divergence of sex development.[338] The changing of the name might lead to the changing of the classifications too. Secondly, certain causes of DSD overlap from one category to another, especially gonadal histological causes which serve as the basis of normal sexual differentiation and anatomical changes.[339] There has been an

[338] J. H. Davies and others, 'Evaluation of Terminology used to Described Disorders of Sex Development', *Journal of Pediatric Urology*, 7 (2011), 412 – 415, p. 412; Morgan Holmes, 'The Intersex Enchiridion: Naming and Knowledge', *Somatechnics*, 1.2 (2011), 388 – 411, p. 388; Elizabeth Reis, p. 535.

[339] Ian A. Aaronson and Alistair J. Aaronson, p. 444.

argument for new classifications based on gonadal histology, by I. A. Aaronson and A. J. Aaronson, as it is the major determinant of clinical outcomes.[340]

Obviously, attaching the types of *khunthā* to current DSD classifications does not guarantee fixed association. Therefore, it is sufficient to exhibit the relationship of *khunthā* and DSD in general terms and explain in detail the shared elements to aim for better understanding. Should there be any changes of the nomenclature, scope or classification, the main concern, i.e. the ambiguity of urine excretion must be clearly understood in relation to *khunthā*.

3.6. Redefining the Term *Khunthā*

It is recorded in pre-Islamic Arab history that ʿĀmir ibn Ẓarib (d. is unknown), who was a judge and a leader in his society was asked about inheritance for a *khunthā*, who was described as retaining male and female genitals.[341] He was unable to make a decision and kept awake all night long to find a solution. His slave girl, Sakhīlah, asked him twice on what had happened. Only then he told her that he was asked about inheritance of a *khunthā* and he could not reach a decision. Sakhīlah suggested for looking into urine excretion and that became the first rule regarding *khunthā* on inheritance in pre-Islamic era.[342] Al-Ḥaṭṭāb al-Ruʿīnī claims that this juridical ruling was first applied in Islamic history by ʿĀlī Ibn Abī Ṭālib (d. 661 AH/1262 CE).[343]

On another occasion, Ibn Qudāmah mentions that in 616 AH (1219 CE) there were two persons identified with ambiguous genitalia. One of them retained no physical characteristics of male or female genitalia except for having a stroma (part of tissue with a structural connective role) for urination.[344] Another person who dressed like a female, mingled with female friends and expressed herself as being female, had only

[340] Ian A. Aaronson and Alistair J. Aaronson, p. 443.

[341] Abū Jaʿfar al-Baghdādī, *Al-Maḥabbar*, ed. by Ilzah Lihktan Shatitar (Beirut: Dār al-Āfāq al-Jadīdah, n.d.), p. 236; Abū al-Fidāʾ Ismāʿīl, *Al-Bidāyah Wa Al-Nihāyah (the Beginning and the Ending)*, ed. by ʿAlī Shīrī, vol. 2 (Beirut: Dār Iḥyāʾ al-Turāth al-ʿArabiy, 1988), p. 262.

[342] Jamāl al-Dīn Ibn al-Jawzī, *Talqīḥ Fuhūm Ahl Al-Athr fī ʿUyūn Al-Tarīkh Wa Al-Siyar (Seeding the Understanding of the Expert of Narration in the Eyes of History and Biography)* (Beirut: Sharikah Dār al-Arqam Ibn Abī al-Arqam, 1997), p. 340.

[343] Al-Ḥaṭṭāb al-Ruʿīnī, Muḥammad ibn Muḥammad, vol. 6, p. 425

[344] ʿAbdullah Aḥmad Ibn Qudāmah, vol. 6, p. 340.

one orifice for urination and defecation.[345] Ibn Qudāmah also states that there was an individual in a non-Arab country who had no orifice but discharged the consumed food and drink through vomiting.[346]

There is no specific literature explaining the basis of defining the term *khunthā.* Perhaps, these live experiences in society did give some insights for the jurists to describe the term. The scope of the definition, however, is limited to the predating of biomedical technology. Nonetheless, it helps, in one way or another, to resolve issues over fulfilling the duties and obligations for Muslims. But it still remains unclear over the medical and legal issues being involved.

Mohd Izhar Ariff Mohd Kashim, a Malaysian scholar in Islamic studies, views physical external observation as sufficient enough to identify a person as a hermaphrodite.[347] Some others would welcome a new definition. Giving new dimensions to classical terms is not new in the Islamic worldview, according to Muhamad Shukri Muhamad, a state Mufti of Kelantan, Malaysia.[348] For example, classical scholars assert that in a marriage, a bride and a groom should present themselves on one occasion (*ittiḥād al-majlis*) with necessary witnesses and guardians. But with the technology today, *ittiḥād al-majlis* can be defined with the presence of the contracting parties even through cyberspace, i.e. through video conferencing. To give another example, based on the Prophet's recommendation, *qiyāfah* or confirmation of lineage was classically deduced from physical resemblance to confirm who the biological father actually was. Nonetheless, data found through Deoxyribonucleic Acid (DNA) is empirically proven to be more accurate and hence is now recognized as a form of proof (*qarīnah*) for supporting evidence (*bayyinah*).

Haneef believes it can be a debatable issue for the proponents of redefining the term.[349] His reason is that science today can resolve an old juridical problem with more precision and hence can substitute *fiqh* postulates on *khunūthah* matters. He assumes that opponents may dispute traditional methods mainly because early corrective

[345] ʿAbdullah Aḥmad Ibn Qudāmah, vol. 6, p. 340.
[346] ʿAbdullah Aḥmad Ibn Qudāmah, vol. 6, p. 340.
[347] Mohd Izhar Ariff Mohd Kashim, *Telephone Conversation with Taqwa Zabidi,* (13 January 2016).
[348] Muhamad Shukri Muhamad, *Telephone Conversation with Taqwa Zabidi* (18 May 2016).
[349] Sayed S. Haneef, *Email to Taqwa Zabidi* (28 May 2016).

surgery will be conducted as soon as the diagnoses take place, although cases of failure to fix genital abnormalities before such individual reach puberty have been documented. Secondly, from the Islamic perspective, redefinition of *khunthā* entails many slippery slopes in terms of ethics and law, on such matters as gender selection and the procedure of invasive surgical interference (pains and emotional scars, and others).

Nevertheless, the researcher believes that *khunūthah* should be redefined by considering the elements of ambiguous genitalia together with atypical chromosomes and gonads. Other respondents of the interview among Islamic scholars support this argument as below:

> "Observation on chromosome, gonad and others is not contradicting with Islam. Furthermore, it can strengthen any decision made."[350]

> "It is possible. That means the *fiqh* books are just a part of it. Based on the research conducted by the doctors, chromosomes and other information become more strong evidences."[351]

Hence, *khunūthah* should be defined as a congenital condition of uncommon presence of genitalia with the disjunction of chromosomal and/or gonadal sex. This is not to say that chromosomes are the determinant factor of gender; or that when they are abnormal, the gender is ambiguous. However, the chromosomes do play an important role, in that their secretion of hormones leads to the forming (or deforming) of what is medically associated with becoming male or female, internally and externally. Throughout this thesis, we are presented with facts to show that redefinition will contribute to a better understanding of *khunthā* and thereby be able to minimize bioethical conflicts.

The importance of this new definition is firstly to clarify that *khunthā* is assumed to be related to the condition of transgender or gender identity disorders. However, the inclusion of the word 'congenital' indicates that the condition is not due to human alteration that is prohibited in Islam, as has been emphasized in the Qurʾān, *Sūrah al-Nisāʾ* (The Women) in verse 119. The second importance of the new definition is that

[350] Islamic Expert 1, *Conversation with Taqwa Zabidi,* (27 August 2015.
[351] Abdul Rahman Osman, *Telephone Communication with Taqwa Zabidi,* (27 February 2016).

the abnormality of the genitals is linked to the chromosomal and gonadal factors excluding any simple defects that are trivial and which have problems that are less common to intersex infants such as having a micropenis for the male or simple labial adhesion for the female.[352] *Khunthā* should not be confused with some cases of genitalia that are 'complex, but local developmental errors, without any identifiable underlying endocrine disorder typical of the intersex patient'.[353]

This definition will eventually lead towards paying more attention to medical and legal aspects as well as physical appearance. As the definition relies on biological aspects, it firstly emphasizes the need for experts, i.e. the physicians' confirmation of the condition. This is regulated in several fatwas given by the Islamic Council for Fatwa Bayt al-Maqdis, the Fatwa Committee of the National Council of Islamic Religious Affairs Malaysia and the Council of Senior Scholars Saudi Arabia.[354]

Furthermore, it educates *khunthā* on their rights to be accorded due treatment and thus be able to enjoy a better quality of health. Besides, gender is a matter with different perspectives of acceptance in most of the countries in this world. Despite the small pressure for 'ungendered' society, some people with *khunūthah* characteristics do now have better access to legal procedures for sex change in identification cards for example as what is being experienced in Malaysia and Indonesia.

In general, the need for redefinition of the term *khunūthah* is firstly to acknowledge the existence and impacts of the biological processes of human development. This particular aspect is able to harmonize the two distinct perspectives of biological human development that essentially share the same root cause. Secondly, it is important to note the dynamic development of the understanding of *khunūthah* from the Islamic perspective and to reject stagnant (*jumūd*) sets of existing knowledge, or concepts that are estranged from biomedical perspectives. Over the past decade, even though

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[352] Ian A. Aaronson and Alistair J. Aaronson, p. 446.

[353] Ian A. Aaronson and Alistair J. Aaronson, p. 446.

[354] The Islamic Council for Fatwa Bayt al-Maqdis, *Taṣḥīḥ Jins Al-Khunthā Bi Wāsiṭah Al-ʿAmaliyāt Al-Jaraḥiah* (Corrective Hermaphrodite's Gender Via Surgery), (Palestine: 2012) [Online] Available at <*http://www.fatawah.net/Fatawah/658.aspx*> [accessed on 12 June 2016]; Department of Islamic Development Malaysia, *Decision of the Fatwa Committee of the National Council for Islamic Religious Affairs Malaysia,* p. 74-75; Ṣāliḥ Fawzān Al-Fawzān, *Al-Fatāwā Al-Mutaʿalliqah Bi Al-Ṭibb Wa Aḥkām Al-Marḍā (Verdicts in Relation to Medicine and Rulings on Patients)* (Riyadh: Riʾāsah Idārah al-Buḥuth al-ʿIlmiyyah wa al-Iftāʾ, 2003), p. 181.

knowledge of human development has undergone extensive expansion, the concept of *khunūthah* still remains as it was. As mentioned in the previous chapter, sharīʿah and science have a close relationship. Therefore, redefining the term *khunūthah* by taking into account both traditional and modern biological perspectives can help bridge the gap between the two. Lastly, a full and correct definition of *khunūthah* can minimize any misleading decisions resulting from limited understanding of the biological conditions.

3.7. Conclusion

This chapter observes the connection between *khunūthah* and DSD. The general concept of gender from both Islamic and medical perspectives provides clear understanding of the two conditions within their own contexts. There are some links between them. There are also other differentiating points between them. Thus, *khunūthah* becomes a part of DSD in a wider biological context. By identifying their connection, it shows that different rights and rules for individuals with *khunūthah* and individuals with DSD can be applied separately. The known facts of human biological development enhance the understanding of the occurrence of *khunūthah*. Redefining the term *khunūthah* acknowledges the scientific facts and definitely contributes to better approaches in managing patients with DSD. These will be sought through further discussions in later chapters by analysing the contexts within the South East Asian region.

4. NEW APPROACH TO GENDER ASSIGNMENT FOR PATIENTS WITH DISORDERS OF SEX DEVELOPMENT (DSD)

4.1. Overview

Medical treatments are inseparable from ethical aspects. A major issue related to managing patients with Disorders of Sex Development (DSD) is how to assign a gender in order to ensure it is compatible for the patient's whole life. Following identification of the relationship between *khunūthah* and DSD, in this chapter, Islamic bioethical underpinnings for DSD conditions that affect gender assignment will be examined. Five approaches to gender assignment will be analysed, including clinical policy, social model, cultural approach, biosocial model and early Islamic practice. A new approach will be introduced from the current perspective of the Islamic ethos. As an extension of Chapter 3, three subcategories indicating the relationship between DSD and *khunūthah* will be reflected within this new approach on how gender assignment should take place.

This topic will not only discuss bioethical issues per se, but also evaluate the methodology used by the Islamic scholars to disentangle these complicated aspects. It is understood from the very first chapter that scholars and jurists have taken very particular steps in comprehending the Highest Intention of the Law Maker (*maqṣad al-shāriʿ*), i.e. God through their interpretation of the revealed texts, the Qurʾān and Ḥadīth, in order to avoid any personal or specific interests or desires. At some points, the methodology that heavily depends on linguistic and textual analysis has been associated with the 'crisis of Islamic thought' as described by Abu Sulayman.[355] It is interesting to evaluate this gap within this study, as the debate on *khunūthah* has barely progressed since the 10th century, yet there has been huge progress from the medical perspective on biological studies and gender ambiguity.

[355] AbdulHamid AbuSulayman, 'Islamization of Knowledge with Special Reference to Political Science', *American Journal of Islamic Social Sciences*, 2 (1985), 263.

4.2. The Necessity for Gender Assignment

Hermaphroditism in cultural discourse was known as 'sacred gender' associated with higher spiritual powers.[356] Hermaphrodites were believed to be mediators between humans and the gods. Different names for the condition are used in different societies in South East Asia. In Indonesia, for instance, *bissu* ('androgynous' deities) is known as the fifth gender after male, female, *calabai* and *calalai* in the Bugis community.[357] *Warok* is the word used in East Java and *wandu* in Java, Indonesia. While in Malaysia, Saskia E. Wieringa, a Dutch sociologist includes *manang bali* as a term used among the Ibanese in the state of Sarawak for transgendered people who play their roles in a ritual context.[358] Unlike *bissu*, manang bali is reported as a group of people who choose to change their own gender. Although Wieringa strongly holds on to the idea of a third gender, she reiterates the views that the downfall of this cultural belief is due to the domination of biomedical discourse and the spread of Islam. However, this cultural perspective is not known among Muslims in Malaysia.

DSD is a condition that requires careful attention due to its complexity and lifelong effects. Assigning a gender is essential with regard to three aspects, i.e. health risks, psychosocial impact and religious obligations for Muslims. In countries that recognize binary sex, it is crucial to treat and assign gender for those affected persons. Even in societies that welcome the third gender, while gender assignment can be compromised, treatment cannot be taken lightly due to health implications such as death risks or tumour development in adulthood. Indirectly, the treatment itself, in certain condition, may lead to the determination of the optimal sex.

Secondly, these issues have psychosocial impacts on both patient and family. The happiness of having a new family member might become 'gender panic' if they notice a baby born with ambiguous genitalia. This leads to anxiety among parents and family. This situation creates a 'medical and psychosocial emergency' that requires

[356] Evelyn Blackwood, 'Gender Transgression in Colonial and Postcolonial Indonesia', *The Journal of Asian Studies,* 64 (November 2005), 849-879, p. 857.

[357] *Calabai* refers to male-bodies individuals, who dress like women, perform women's roles, and have male partners. *Calalai* refers to female-bodies individuals who may live with their women partners and play their roles as males.

[358] Saskia E. Wieringa, 'Gender Variance in Asia - Discursive Contestations and Legal Implications', *Gender, Technology and Development,* 14 (2010), 143-172, p. 151.

immediate attention and resolution. In societies in which DSD is not recognized, as reported by Annastasia Ediati in Indonesia, persons reared as females, who later experience as males, trigger negative acceptance among communities.[359] The same stigmatization occurs in Malaysia, as reported by Ani Amelia Zainuddin.[360]

In 2015, Zainuddin forwarded a case to JAKIM to confirm gender status of a patient, named in this thesis as 'CC'. This patient was identified as a male at birth with atypical male genitalia. CC had strong female gender identity and had atypical pubertal development. CC had Sex Assignment Surgery (SAS) at age 22 as female. Two years later, she converted to Islam.[361] After her gender status was confirmed by the Shariah Expert Panel, JAKIM, she shared her experience converting to Islam in a Facebook page and the video spread everywhere. Despite the support of the Muslim community, many comments were posted by the netizen about her sex change. Most of them were from Malaysia, who had been her friends, colleagues and teachers criticising *him* for claiming to be female and for manipulating the religion to justify the sex change.[362] In general, the stigmatization may lead the affected persons to withdrawal from social relationships; make the decision not to seek medical treatment.[363]

Thridly, for Muslim patients, the requirement of gender assignment is crucial for them to perform their religious obligations, especially on those gender-accentuanted obligations. While both males and females are obliged equally to perform their duties, there are a few differences on how to perform the obligations such as in individual prayer, congregational prayer and in segregating inheritence. Further description that indicates various gender differentiation for religious obligations can be found in Appendix C.

[359] Annastasia Ediati, Nani Maharani and Agustini Utari, 'Sociocultural Aspects of Disorders of Sex Development', *Birth Defects Research Part C, Embryo Today, Reviews,* 108 (2016), p. 381.

[360] Ani Amelia Zainuddin, *Skype Conversation with Taqwa Zabidi* (20 July2016).

[361] Ani Amelia Zainuddin and others, *Islamic Perspectives of DSD and Gender-Related Issues,* Ghent, Belgium edn, 5th I-DSD Symposium Programme, (United Kingdom: I-DSD Registry, University of Glasgow, 2015); Ahmad Tarmizi Mahmud, *Hukum Penetapan Jantina Bagi Pesakit H (Rulings on Gender Assigment for H),* Kertas Kerja Mesyuarat Panel Pakar Syariah Jabatan Kemajuan Islam Malaysia (Paperwork of Shariah Expert Panel Meeting, Department of Islamic Development Malaysia), vol. 88 (Putrajaya: 2015), 1 – 36, pp. 2 – 4.

[362] Facebook I convert to Islam. 7 September 2017.

[363] Annastasia Ediati, Nani Maharani and Agustini Utari, 'Sociocultural Aspects of Disorders of Sex Development', *Birth Defects Research. Part C, Embryo Today, Reviews,* 108 (2016), p. 381.

Following the Chicago Consensus, as explained in subtopic 3.4, Chapter 3, a working group was established to develop DSD core dataset. In 2011, the initiative was expanded to collect data on DSD cases from all over the world and it is currently hosted at the University of Glasgow, United Kingdom.[364] It is known as International DSD (I-DSD) Registry. In order to observe prevalence of cases in Muslim countries, the researcher requested for the data in 2016 from the I-DSD Registry. The data was limited as it is based on the contribution of information by DSD medical experts in particular countries. It shows that across 4 general classifications of DSD in Egypt, 68 were assigned as males and 62 were assigned as females. In Turkey, 240 were assigned as males and 151 were assigned as females. Meanwhile, 2 others from each country were not assigned any gender.[365]

The pattern varies, depending on numerous factors, in assigning gender. In cases handled by medical practitioners, the biological factors typically remain the most pertinent aspect to be taken into account. Undeniably, the basis of the decision-making is more than the medical approach. Social, cultural and religious factors also influence outcomes. We will discuss this thoroughly in a later chapter on related parties who contribute to these determinants. Meanwhile, the subsequent discussion will incorporate analysis of the determinants of gender assignment from sharīʿah perspectives of this issue.

4.3. Approaches to Gender Assignment

The main goal in the treatment of DSD is to have gender assignment and at best to be consistent with gender identity in order to prevent gender dysphoria.[366] For neonates with major genital anomalies, assignment of sex during rearing is a central issue, as it affects his/her gender identity to meet societal expectations of gender roles, not to mention the health impact of the surgical intervention and lifelong sex-hormone

[364] I-DSD Registry, 'International DSD Registry Newsletter', Autumn 2012, <https://home.i-dsd.org/newsletter-archive/> [23 November 2015].

[365] Data collected from I-DSD/CAH Registry, University of Glasgow, 26 August 2016.

[366] A. D. Fisher and others, 'Gender Identity, Gender Assignment and Reassignment in Individuals with Disorders of Sex Development: A Major Dilemma', *Journal of Endocrinological Investigation,* 39 (2016), 1207-1224, p. 1207.

administration.[367] The conundrum here is the outlook of the terms sex and gender. Money proposes:

> "Sex is what you are biologically; gender is what you become socially; gender identity is your own sense or conviction of maleness or femaleness; and gender role is the cultural stereotype of what is masculine or feminine".[368]

The spectrum of these terms is widespread. Most recent research differentiates the particular scope of the gender they are focusing on. While biological studies focus on sex; sociologists and anthropologists focus on gender and how it is constructed. On the other hand, Islamic scholars focus on Divine Revelations to determine the sex.

In Arabic, there are no specific terms to identify the difference between sex and gender. Both are known as *al-jins* (**الجنس**) when referring to sex, i.e. masculinity and femininity. *Al-jins* is used indistinctively for sex and gender. The term also refers to sexual intercourse.[369]

However, *al-jins* is never mentioned in the Qurʾān. In expressing those terms, the Qurʾān uses the words *zakr* (male) and *unthā* (female) or the words *al-rijāl* (men) and *al-nisāʾ* (women) in relation to two folds. Firstly, in the Qurʾān, they are used in relation to human creation, which is closely related to biological sex. For example, verse 1 of Sūrah al-Nisāʾ says:

> "O mankind! Reverence your Guardian-Lord, who created you from a single person, created, of like nature, His mate, and from them twain scattered (like seeds) countless men (*rijāla*) and women (*nisāʾa*);"[370]

Secondly, those Qurʾanic terms are used in relation to human actions, rights, and obligations, as stated in this verse:

> "Whoever works righteousness, man or woman (*al-zakr wa al-unthā*), and has Faith, verily, to him will We give a new Life, a life that is good and pure and We will bestow on such their reward according to the best of their actions."[371]

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[367] Rabah M. Shawky and Sahar M. Nour El-Din, 'Profile of Disorders of Sexual Differentiation in the Northeast Region of Cairo, Egypt', *Egyptian Journal of Medical Human Genetics*, 13 (2012), 197-205, p. 203.

[368] J. Money, J. G. Hampson and J. L. Hampson, 'Hermaphroditism: Recommendations Concerning Assignment of Sex, Change of Sex and Psychologic Management', *Bull Johns Hopkins Hospital*, 97 (1955), 163.

[369] Aḥmad Muḥammad Kanʿān, *Al-Mawsūʿah Al-Ṭibbiyyah Al-Fiqhiyyah (the Encyclopedia of Medical Islamic Jurisprudence)*, 2nd edn (Beirut: Dār al-Nafāʾis, 2006), p. 280.

[370] The translation of the Qurʾān, in ʿAbdullah Yūsufʿ Alī, *The Holy Qur´an Text, Translation and Commentary*, New Revised edn (Brentwood: Amana Corporation, 1989), *Sūrah al-Nisāʾ* (The Women), 4: 1.

[371] The translation of the Qurʾān, in ʿAbdullah Yūsufʿ Alī, Sūrah *al-Naḥl* (The Bee), 16: 97.

The actions are not limited to individual-ritual deeds, but also include obligations and responsibilities in a larger context even at the societal level. Technically, the use of the words suggests the connection between internal bodily features and the external capabilities in carrying out the duties. Thus, it is clear that the Qurʾanic view of terminology on sex and gender is inseparable. There is no cross-relation on sex and gender, as they are considered a dual and parallel concept.

As scientific knowledge progressed, the term الجندر - *al-jandar* was introduced in contemporary Arabic to translate the word gender in English. The researcher will not prolong the discussion of the terms sex and gender in Islam, but to use them interchangeably as they have been used, unless it is necessary to highlight their differences.

4.3.1. Clinical Policy in Gender Assignment

The advancement of biomedical technology has expanded knowledge of human biological development and its disorders. It is not the researcher's intention to evaluate clinical methods, which are beyond the objectives of this research. However, to analyse Islamic biomedical ethics pertaining to DSD, it is crucial to understand the clinical techniques used to identify gender. In Chapter 3, we reached the understanding that not all DSD cases are *khunūthah* due to the presence (or absence) of ambiguous genitalia and dual genitals.

No standard guideline has been proposed by medical practitioners to assign gender, as has been proposed by Muslim scholars. This may be due to various patterns of disorders and the wide spectrum of differential diagnoses. There is also no single set of guidelines to evaluate DSD according to medical knowledge.[372]

As mentioned in the previous chapter, understanding sexual determination and sexual differentiation in human biological development is vital in assigning the gender.

[372] Berenice B. Mendonca, 'Gender Assignment in Patients with Disorder of Sex Development', *Current Opinion Endocrinology, Diabetes and Obesity*, 21 (2014), 513.

Discrepancies at any stage of sexual development provide the basic explanation of such disorders. The diagnosis of DSD might be early, in an infant or late, in an adult. The investigation of infants is conducted when the genital appearance is so ambiguous that sex assignment is impossible at birth, or when the genital appearance is discordant with the prenatal genetic test.[373] Mendonca views diagnosis as important to predict gender identity, in addition to identifying endocrine function, fertility potential, and the risk of developing tumours at adulthood.[374]

The prediction of sex is based on the most likely type of gender in terms of chromosomes, hormones, genetic make-up, internal and external genitalia, and the debatable aspect of psychosexual orientation.[375] The chromosomes alone might not conclusively suggest a certain gender. For example, Congenital Adrenal Hyperplasia (CAH) is categorized under 46,XX DSD classification, as discussed in Chapter 3. The chromosomes, 46,XX is generally a female determinant and most of the cases with it are assigned as female. However, 5% of them were identified as males.[376] Complete Androgen Insensitivity Syndrome (CAIS) is another clear example. Patients with this type of DSD normally have 46,XY chromosomes, a male chromosomal determinant. However, due to androgen insensitivity, which is the hormone that stimulates or controls the development of male characteristics, external genitalia may be completely female. This genotype data should be observed together with the phenotype evidence. Though, the prediction may sometimes stumble, especially if the diagnosis is uncertain, leading to inappropriate gender identity that requires sex reassignment at a later age.[377]

[373] S. Faisal Ahmed and others, 'Society for Endocrinology UK Guidance on the Initial Evaluation of an Infant and Adolescent Suspected with Disorders of Sex Development (Revised 2015)', *Clinical Endocrinology,* (2015), 1-18, p. 6.

[374] Berenice B. Mendonca, p. 513.

[375] See argument in subtopic 4.3.5 in this chapter on element of psychosexual orientation as a determinant of gender assignment.

[376] RW Dittmann, ME Kappes and MH Kappes, 'Sexual Behavior in Adolescent and Adult Females with Congenital Adrenal Hyperplasia', *Psychoneuroendocrinology,* 17 (May - Jul 1992), 153-170, p. 164; Kenneth J. Zucker and others, 'Psychosexual Development of Women with Congenital Adrenal Hyperplasia', *Hormones and Behavior,* 30 (1996), 300-318.

[377] Nabil M. Dessouky, 'Gender Assignment for Children with Intersex Problems: An Egyptian Perspective', *Egyptian Journal of Surgery,* 20 (April 2001), 499-511, p. 499.

4.3.2. Social Model of Gender Assignment

The social model is referred to in the theories that believe in social forces or nature as the construction of gender. In the 1950s, optimal gender policy was introduced by John Money and his colleague at the John Hopkins School of Paediatric and Endocrinology. This policy aims for good reproductive function, good sexual function, minimal medical procedures, an overall gender-appropriate appearance, a stable gender policy and a reasonably happy life.[378] Money opines that sex can be nurtured and it is not nature. Sex assignment and rearing, according to Money, is more reliable when compared to chromosomal sex, gonadal sex, hormonal sex, accessory internal reproductive morphology and ambiguous morphology of external genitalia.[379] In other words, the assignment is not clinically driven but socially constructed. Sexuality is learnt and nurtured in the same ways we learn everything else.[380] John Gagnon, a pioneer sociologist on human sexuality states:

> "At the present time, the belief in powerful [biological] sex drives seems quite implausible. Most psychologists…prefer to argue that human beings are active and energetic organisms that are capable of learning how to be sexual in the same ways that they learn everything else. What we need to do is begin to look at how the environment promotes or does not promote various kinds of sexual activity."[381]

Some scholars claim that "evidence for the notion that much social behaviour is determined by hormones is simply nonexistent."[382] It is the social factors that mould the upbringing such as giving names, dressing children with sex-dimorphic colour coding, buying toys based on sex roles etc. Supporting this claim, American Academy Paediatrics had once provided a statement that:

> "Research on children with ambiguous genitalia has shown that a person's sexual body image is largely a function of socialization, and children whose genetic sexes are not clearly reflected in external genitalia can be raised

[378] Heino F. L. Meyer-Bahlburg, 'Gender Assignment in Intersexuality', *Journal of Psychology & Human Sexuality,* 10 (1998), 1-21, p. 2.

[379] John Money and A. A. Ehrhardt, *Man and Woman, Boy and Girl: Gender Identity from Conception to Maturity* (Baltimore: The John Hopkins University Press, 1973), p. 33.

[380] John Gagnon, *Human Sexualities* (Glenview: Scott Foresman, 1977), p. 11.

[381] John Gagnon, p. 11.

[382] Joyce McCarl Neilsen, *Sex and Gender in Society*: *Perspectives on Stratification*, 2nd edn. (Illinois: Waveland Press Incorporated, 1990).

> successfully as members of either sex if the process begins before 2 ½ years."[383]

Meyer-Bahlburg holds that this policy is unlikely to be accepted by religious scholars such as those in Judaism and Islam, as they favour true biological sex.[384]

This policy was challenged when a normal XY (male) twin who was assigned the gender of girl, as an infant by Money and his team requested sex reassignment at a later age. In this case, Joan (not a real name) was brought up as a girl from 8 month of age due to *her* penis being burnt to ablation during phimosis repair by cauterization. Joan underwent surgery to fashion a full vagina. The notions behind the decision were based on two postulates: i) that the psychosexual identity of individuals is neutral at birth; and ii) the appearance of genitals provides healthy psychosexual development.[385]

The Joan case was later studied by Milton Diamond, who co-authored with H. Keith Sigmundson in 1997. The experiment to bring up the child as a girl despite his initial male biological development failed. Joan requested sex reassignment at puberty to live as a boy. The case demonstrated the devastating amount of suffering that he had had to bear throughout his childhood and adulthood until he died at 38 years old. Diamond and Sigmund interpreted the case as 'evidence of innate biological forces in sexual identity development sufficient to overcome the extensively imposed environmental influences'.[386]

4.3.3. Cultural Approach to Gender Assignment

Culture, beliefs and preferences are interconnected in shaping decisions of gender identity. Culture is closely related to social factors on how societies look, believe and practice certain actions. It is related to ideas, customs and the social behaviour of a

[383] Intersex Society of North America, *Intersex Society of North America;* isna.org edn, News Release: American Academy of Pediatrics Position on Intersexuality, 2016 (North America: Intersex Society of North America; 2008).

[384] Heino F. L. Meyer-Bahlburg, p. 2.

[385] Milton Diamond and H. Keith Sigmundson, 'Sex Reassignment at Birth: Long-Term Review and Clinical Implications', *Pediatrics and Adolescent Medicine*, 151 (1997), 299.

[386] Milton Diamond, 'Foreword: Sexual Development - Nature's Substrate for Nurture's Influence', in *Males, Females, and Behavior toward Biological Understanding*, ed. by Lee Ellis and Linda Ebertz (Westport: Praeger, 1998).

particular people or society. Culture, according to United Nations Educational, Scientific and Cultural Programme (UNESCO), should be regarded as:

> '[the] distinctive spiritual, material, intellectual and emotional features of society or a social group, and that it encompasses, in addition to art and literature, lifestyles, ways of living together, value systems and beliefs.'[387]

Some researchers argue that determinants of gender assignment, as discussed in Chapter 3, are not limited to biological and social factors. As early as 1935, Margaret Mead emphasized cultural determination of gender.[388] Later, in 1957, Barry, Bacon and Child conducted a study to evaluate whether the patterns of behaviour are genetically constructed or function as nearly universal cultural practices.[389] Though, culture is an external factor that should not be understood as a sex determinant because it diverges from what has been discussed in the previous chapter. Rather, it is a contributing factor that should be taken into consideration in the decision making phase.

It is noticed that cultural influence on child-gender preference is recorded in the Qurʾān as existing since pre-Islamic era. It is mentioned in the Qurʾān:

> "When news is brought to one of them, of (the birth of) a female (child), his face darkens, and he is filled with inward grief! With shame does he hide himself from his people, because of the bad news he has had! Shall he retain it on (sufferance and) contempt, or bury it in the dust? Ah! What an evil (choice) they decide on?"[390]

People in that particular era believed that female newborns would only bring humiliation to the family, while male babies would bring good fortune. Thus, sons were welcomed and brought up by the family, while females were buried alive. As the times changed and awareness developed, the practice of burying female babies faded. However, the preference for sons remains due to socio-economic circumstance, marriage and infertility and religious factors. Apparently, the reason for sons being preferred are different between pre and post periods of ignorance. But the point is,

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[387] United Nations, Educational, Scientific and Cultural Organization, *UNESCO Universal Declaration on Cultural Diversity,* Records of the General Conference (Resolution 25), trans. by United Nations, Educational, Scientific and Cultural Organization, (Paris: United Nations, Educational, Scientific and Cultural Organization, 2001).

[388] Margaret Mead, 1935, Sex and Temperament in Three Primitive Societies, New York, Wm. Morrow.

[389] Herbert III Barry, Margaret.K. Bacon and Irvin L. Child, 'A Cross-Cultural Survey of Some Sex Differences in Socialization', *The Journal of Abnormal and Social Psychology*, 55 (1957), 327 - 332

[390] The translation of the Qurʾān, in ʿAbdullah Yūsufʿ Alī, *Sūrah al-Naḥl* (The Bee), 16: 58-59.

culture has its own capacity for influencing a community towards such gender preference.

Coincidently, male gender is still favoured within certain contemporary Muslim communities, despite the progressive enlightenment period. Dessouky reports that Egyptians favour the male gender for many reasons, some of which are influenced by religious perspectives.[391] For example, a male inherits double the amount of a female, males are obliged to perform essential daily prayers at the mosque rather than performing them at home as females do, and a male witness' testimony considered double the worth of a female's. It should be noted here; these assumptions are unlikely to be regarded as religious perspectives. Instead, they are cultural beliefs that are linked to religious deeds. Religious obligations as a determinant of gender assignment are unfounded in sharīʿah. Although certain rights and obligations in Islam are closely related to gender in fulfilling their performance, they should not be the ways of recognizing the preferred gender. Certainly, gender preferences and assignment should not be used in order to secure particular rights and benefits. The arguments for putting religious actions first are inadequate and insubstantial. Individuals' obligations and their rules should come after gender assignment and not vice versa.

Another aspect of gender assignment is associated with infertility. It is clear that this health implication of reproduction is one of the major concerns with regard to DSD conditions. It is also reported by Rabah M. Shawky and Sahar M. Nour El-Din that female infertility precludes marriage which also affects employment prospects in Egyptian society. Hence, male gender is favourable to female in order to secure economic independence.[392] The figures from their report, are that 60.35% of intersex patients were reared as male and 39.64% were reared as female.[393] Similarly in Turkey, males are preferable due to a combination of cultural, economic and social factors. Males are considered to be the traditional breadwinners and play dominant roles in society. Females, on the other hand, play their roles at the domestic level. Thus, shaping the parental preference for males in assigning the gender.[394]

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[391] Nabil M. Dessouky, p. 512.
[392] Rabah M. Shawky and Sahar M. Nour El-Din, p. 203.
[393] Rabah M. Shawky and Sahar M. Nour El-Din, p. 203.
[394] Hüseyin Özbey and Seref Etker, 'Disorders of Sexual Development in a Cultural Context', *Arab Journal of Urology*, 11 (2013), 33 – 39, p. 36.

The attachment of certain groups of the community to their own religions shapes their cultural tendency in gender selection. Likewise, the Chinese community in Malaysia is reported to have son preference even though the Chinese fertility has dropped rapidly since 1970.[395] It is due to the desire for continuation of the family name which is attributable for the influence of traditional Confucian ideas.[396] This practice is irrelevant to Malay and Indian communities as the children are identified with *bin* (son of) and *binti* (daughter of) or 'son of' and 'daughter of' by those races respectively. Chinese families are described as patrilineal, patrilocal and patriarchal. They are led by men, the guarantor of family continuation.[397] Family ties and continuation are extremely important for successful business and a similar pattern is practised when the Chinese are a majority or minority group in their own country such as in Singapore and Malaysia.[398] There is little evidence to conclude sex preference among Indians since the population is significantly low, in Malaysia and the sample size is small. The case examples were different in Chinese and Indian families. The former, in some cases, discontinue the diagnosis and treatment when a female gender was suggested.

On the contrary, the Malay community in Malaysia has no clear preference on a child's gender. Kunhle and Krahl's experiences indicate that 'it was never difficult to convince a Muslim family to assign a severely virilised girl or an undervirilised boy to the female gender'.[399] This observation strengthens a study conducted by Suet-ling Pong in 1994 that shows inconsistency of sex preferences among Malays with different numbers of children.[400] Malays are regarded as Muslims. Yet, the sex preference in the Middle East countries, which is assumed to be Islamic underpinning does seem inconsistent with Malay Muslim culture. Men and women play equal social development roles in the Malaysian context. Malay women are independent in the sense that they are free

[395] Suet-ling Pong, 'Sex Preference and Fertility in Peninsular Malaysia', *Studies in Family Planning,* 25 (May - June 1994), 137 148, p. 137; Victor J. Callan and Poo-Kong Kee, 'Sons or Daughters? Cross-Cultural Comparisons of the Sex Preferences of Australian, Greek, Italian, Malay, Chinese and Indian Parents in Australia and Malaysia', *Population and Environment,* 4 (1981), 97-108, p. 107.

[396] Victor J. Callan and Poo-Kong Kee, p. 107.

[397] Helen Kopnina, 'Family Matters? Recruitment Methods and Cultural Boundaries in Singapore Chinese Small and Medium Enterprises', *Asia Pacific Business Review,* 11 (2005), 483-499, p. 483.

[398] Helen Kopnina, p. 490; Suet-ling Pong, p. 144.

[399] Ursula Kuhnle and Wolfgang Krahl, 'The Impact of Culture on Sex Assignment and Gender Development in Intersex Patients', *Perspectives in Biology and Medicine,* 45 (2002), 85-103, p. 94.

[400] Suet-ling Pong, p. 142.

to mingle within the society, have access to education and profession, hold important posts in their career and manage their own wealth and properties. In addition to Islamic context, they are entitled to inherit and control their own money.

4.3.4. Biosocial Model of Gender Assignment

New long-term research provides other recommendations towards improving the clinical policy for gender assignment, either by emphasizing the biological factors and/or acknowledging the psychosexual orientation and socio-cultural impact in assigning the 'correct' gender.[401] Zucker emphasizes the importance of both perspectives, because it is difficult to consider them in isolation. In typical individuals, the gender of rearing is usually congruent with the assigned sex. Thus, biological and psychosocial influences are typically inextricably intertwined.[402]

In response to the opinions about nurture psychosocial and psychosexual development, Robert H. Lustig states that hormonal activities activate brain sex differentiation in terms of cognition, behaviour and possibly sexual orientation. Brain sex differentiation may therefore have been influenced by sex hormonal modulation of neural development. Research into in-vitro models of these phenomena among rats shows that, in brief, oestrogen and androgen have an influence on intraneural communication and interneuronal contact, respectively, in the brain.[403] Excessive exposure to, or lack of, antenatal androgen, for example, leads to changes of structure and function of the brain in adulthood.

[401] Suzanne J. Kessler, 'The Medical Construction of Gender: Case Management of Intersexed Infants', *Signs*, 16 (1990) 3 – 26, p. 24; Heino F. L. Meyer-Bahlburg, Gender Assignment, p. 21; Kenneth J. Zucker, 'Evaluations of Sex- and Gender-Assignment Decisions in Patients with Physical Intersex Conditions: A Methodological and Statistical Note', *Journal of Sex & Marital Therapy*, 28 (2002), 269-274, p. 273; Rabah M. Shawky and Sahar M. Nour El-Din, p. 203.

[402] Kenneth J. Zucker and others, 'Psychosexual Development of Women', p. 301.

[403] Robert H. Lustig, 'Sex Hormonal Modulation of Neural Development in Vitro: Implication for Brain Sex Differentiation', in *Males, Females and Behavior: Toward Biological Understanding*, ed. by Lee Ellis and Linda Ebertz (Westport: Preager, 1998), p. 24. Oestrogen is one of a group of steroid hormones that control female sexual development, promoting the growth and function of the female sex organs and female secondary sexual characteristics. The definition is based on *Concise Medical Dictionary*, 8th edn (Oxford: Oxford University Press, 2010). [Online] Available at <https://www-oxfordreference-com.ezproxy.uwtsd.ac.uk/view/10.1093/acref/9780199557141.001.0001/acref-9780199557141> [accessed 15 November 2016].

David E. Comings also states that human sexual behaviour is genetically influenced. Some genetic components were found related to sex drive, sexual orientation, exhibitionism, transvestism-transexualism, sadism-masochism, paedophilia and fetishism, and aversion to sex.[404] His study suggests that sexual behaviour is not solely influenced by the environment, as genetics too play an important role in the development of behaviour.

Giordano concludes that both models (nurture/nature) cannot be taken separately. Neither of them would work without absolute deference to clinical practice. Although gender identity is a learnt process, as Gagnon states, gender itself cannot be moulded by rearing only since biological facts are the determinants.[405] The model is observed in Malaysian Paediatric Protocol. The Protocol recommends five factors for gender assignment for infants: diagnosis; fertility potential and adequacy of genitalia for sexual function; endocrine function of gonads; parents' socio-cultural background, i.e. expectations and acceptance; and psychosocial development in older children.[406]

4.3.5. Early Islamic Practices in Gender Assignment

In the pre-Islamic era, a judge who was asked about *khunthā* agreed with his servant's suggestion to ascertain whether such a person was male or female, one may examine the way he or she urinates.[407] This decision is among pre-Islamic practices that have been applied in Islam ever since. The hypothetical technique is based on *al-mabāl* or urethra, a tube that allows the urine to pass out from the body. As the urethra is an internal organ that typically went unexamined without the help of biomedical technology, the only accessible external organ was the genital, known in *fiqhi* books as *al-ālah* i.e. the medium through which the fluids from the body can be excreted. Sunni scholars of all four schools of thought have agreed that the external genitalia

[404] David E. Coming, 'Some Genetic Aspects of Human Sexual Behavior', in *Males, Females and Behavior: Toward Biological Understanding*, ed. by Lee Ellis and Linda Ebertz (Westport: Preager, 1998), pp. 11-12.

[405] Simona Giordano, *Children with Gender Identity Disorder - A Clinical, Ethical and Legal Analysis* (New York: Routledge, 2013), p. 19.

[406] Hussain Imam Muhammad Ismail, Ng Hoong Phak and Terrence Thomas, *Paediatric Protocols for Malaysian Hospitals*, 3rd edn (Putrajaya: Kementerian Kesihatan Malaysia, 2013), p. 269.

[407] Please refer to subtopic 3.6, Chapter 3 for further reading.

indicate the gender for newborns and children.[408] Ibn Qudāmah identifies this criterion as based on a Ḥadīth narrated from the Prophet as below:

> The Prophet (peace be upon him) was asked about a newborn who possessed both vagina and penis, how is the baby's inheritance? He replied, "the baby's inheritance is based on his or her urine excretion".[409]

Inheritance in Islam is emphasized in the verses 11 and 12, *Sūrah al-Nisāʾ* of the Qurʾān. The wealth division is strictly based on gender. If a baby's gender is ambiguous, this triggers the question of how the baby is to inherit. Although the core subject of the Ḥadīth is pertaining to the inheritance, it depicts the method of gender assignment. However, the authority of this particular Ḥadīth as an instrument in deducing such ruling in *ʾuṣūl al-fiqh* is doubtful because Al-Bayhaqī (d. 458 AH /1065 CE) states that Muḥammad Ibn al-Sāʾib al-Kalbī (d. 146 AH/763 CE), one of the narrators of the Ḥadīth, was unreliable and Ibn al-Bayʿ in his *Al-Madkhal ilā al-Ṣaḥīḥ* lists him as a liar.[410] The Ḥadīth is considered weak due to the presence of a single weak narrator in the chain of transmission (*isnād*) because there is no other channel with good *isnād* to upgrade the level of authority of the Ḥadīth within the same subject matter. Therefore, to claim this is a saying of the Prophet is a misleading statement.

What is left are *athār* (narrations or sayings) of ʿAlī Ibn Abī Ṭālib (d. 40 AH/661 CE), the most recorded narrations, as documented by ʿAbd al-Razzāq al-Ṣanʿānī (d. 211 AH/826 CE) in his *Muṣannif*. Besides, there are also narrations related to ʿUmar (23 AH/644 CE); Saʿīd Ibn al-Musayyib (d. 93 AH/711 CE); al-Shaʿbī (d. 104 AH/722 CE) and Abū Jaʿfar (d. 114 AH/732 CE).[411] They all assert that *khunthā's* inheritance is based on his/her urine excretion. ʿAlī Ibn Abī Ṭālib's companions witnessed that he

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[408] Muḥammad Ibn Aḥmad Al-Sarakhsī, *Al-Mabsūṭ (The Outstretched*), (Beirut: Dār al-Maʿrifah, 1993), p. 103; Aḥmad Idrīs Al-Qarāfī, *Al-Ḏakhīrah (The Repository),* ed. by Muḥammad Ḥujjī, 1st edn, (Beirut: Dār al-Gharb al-Islāmīy, 1994), p. 23; ʿAlī Ibn Muḥammad Al-Māwardī, *Al-Ḥāwī Al-Kabīr fī Al-Fiqh Al-Mazhab Al-Imām Al-Shāfiʿī Wa Huwa Sharḥ Mukhtaṣar Al-Muzannī (The Great Enclosure of Understanding Shāfiʿī School of Thought)*, ed. by ʿAlī Muḥammad Muʿawwaḍ and ʿĀdil Aḥmad ʿAbd al-Mawjūd, 1st edn (Beirut: Dār al-Kutub al-ʿIlmiyyah, 1999), p. 380; ʿAbdullah Aḥmad Ibn Qudāmah, *Al-Mughnī (The Enricher)* (Cairo: Maktabah al-Qāhirah, 1963), p. 336.

[409] Aḥmad Ibn Al-Ḥusayn Al-Bayhaqī, *Al-Sunan Al-Kubrā (Grand Traditions),* ed. by Muḥammad ʿAbd al-Qādir ʿAṭā, vol. 6 (Beirut: Dār al-Kutub al-ʿIlmiyyah, 2003), p. 428. Ḥadīth no. 12518, *Kitāb al-Farāiḍ* (Book of Laws of Inheritance), *Bāb Mirāth al-Khunthā* (Chapter Inheritance of Hermaprhodites).

[410] Al-Ḥākim Muḥammad Ibn Al-Bayʿ, *Al-Madkhal Ilā al-Ṣaḥīḥ (Introduction to the Authentic),* ed. by Al-Mikhail, Rābiʿ Hādī ʿUmayr (Beirut: Muʾassasah al-Risālah, 1404H), p. 195.

[411] ʿAbd al-Razzāq Ibn Hammam Al-Ṣanʿānī, *Muṣannif (the Classified),* ed. by Ḥabīb Al-Raḥman Al-Aʿẓamī, vol. 10 (India: Al-Majlis al-ʿAlamī, 1403H), p. 308.

said, “Kindly look at where the urine is excreted from, for there he/she inherits”.[412] ʿUmar, the second caliph, was recorded by Ibn Abī Shaybah (d. 235 AH/849 CE) to convey the same opinion.[413] While Saʿīd Ibn al-Musayyib adds that in the event of having dual genital, “if the urine is excreted through both organs, the one that functions earlier shows the dominant gender”.[414] These narrations are regarded as the companions’ sayings (*qawl al-ṣaḥābī*) and are recognized unanimously by Sunni scholars as proof of injunctions, especially when there is not a single disagreement on the matter.[415] Thus, their assumptions are legally acknowledged in the principles of Islamic jurisprudence.

Every *fiqhi* book explains *khunūthah,* purposefully discussing religious obligations, and never fails to explore gender assignment. These scholars blend the Qurʾanic texts on human creation and the common human bodily functions. The rationale of looking at the genitalia for gender assignment is that the organs, i.e. penis and vagina are useful to identify the difference between man and woman. Al-Mawardī contends that each organ represents one gender. He states that dual genital persons cannot retain dual gender, may not choose to be ungendered, or insist on being partially man and woman.[416] A common function of the genitalia is for urine excretion, besides its specific function as a medium of reproduction. He concludes that common functions become the basis in seeking the correct gender of *khunthā.*[417]

As mentioned in Chapter 3, the condition of a *khunthā* is illustrated as either having an orifice, an ambiguous organ, or two genitalia. Based on the *ḥukm al-mabāl* (attribution to urinary tract) approach, the scholars seem to focus only on the dual genital condition. There was no empirical research to be relied upon at that time and the rulings were deduced based on the preponderance technique (*tarjīḥ*), i.e. weighing

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412 Aḥmad Ibn Al-Ḥusayn Al-Bayhaqī, vol.6, p. 427. Ḥadīth no.: 12513.

413 Abū Bakr Abū Shaybah, *Al-Kitāb Al-Muṣannif fī Al-Aḥādīth Wa Al-Athār (Book of the Classified on Ḥadīth and Narrations)*, ed. by Kamāl Yūsuf Al-Ḥūt, vol. 6 (Maktabah al-Rushd, 1409H), p. 277. No. Ḥadīth: 31365.

414 Abū Bakr Abū Shaybah, vol. 6, p. 277. Ḥadīth No.: 31366.

415 Muḥammad Muṣṭafā Al-Zuḥaylī, *Al-Wajīz fī ʾUṣūl Al-Fiqh Al-Islāmī (Comprehensive Principles of Islamic Jurisprudence)*, 2nd edn (Damascus: Dār al-Khayr, 2006), p. 272. For English reference, see further in Abu Umar Faruq Ahmad and Farrukh Habib, 'Authority of Qawl Al-Sahabi in Islamic Fiqh and its Application in Modern Islamic Finance', *SSRN Electronic Journal*, (2014) [accessed 23 June 2016].

416 ʿAlī Ibn Muḥammad Al-Māwardī, vol. 11, p. 410.

417 ʿAlī Ibn Muḥammad Al-Māwardī, vol. 11, p. 410.

of conflicting or incongruent evidence for decisions in Islamic jurisprudence. The *tarjīḥ* in *khunthā* is by precedence, strength, and endurance, in sequence. For example, when both genitalia function simultaneously, the precedent genital excreting the urine suggests the correct gender. However, the scholars differ in their understanding of *tarjīḥ* by strength, as it is considered in terms of the amount of urine. Abū Ḥanīfah and Abū Yūsuf oppose the measuring of urine for two reasons. Firstly, the amount of urine depends on the size of the bladder (the muscular that collect urine from the kidney). They argue that women's bladders are wider than men's, which nullifies the hypothesis. Secondly, which is more important, urine itself does not verify the subject of argument, namely urethra. It is also unpractical for the judge to measure the urine.[418]

The 'attribution to the urinary tract' approach seems more applicable prior puberty. During puberty, the signs of masculinity and femininity become more apparent and can be observed whenever the evidence of urine excretion is weak. Throughout the 30 classical *fiqhi* books, across four Sunni schools of thought, that have been analysed, the researcher found that none of the texts explains the methodological concepts used to identify those signs. Perhaps with the light of the Qurʾān and Ḥadīth, they rely on the texts and consider common observable features of human development. Al-Ḥaṭṭāb al-Ruʿīnī states that the method of seeking for critical assumptions is legally accepted in Islamic juridical thoughts.[419] Al-Ruʿīnī's argument is based on exegesis of the Qurʾān on the incidents that happened to the Prophet Yūsuf as the signs (ʿ*alāmāt*) suggested the actual situations.

The first and second features of gender that are visible after puberty are related to menarche as the sign for females and ejaculation for males within the expected age. In order to ensure the reliability of these features, thorough exploration and careful explanations of the types of blood, semen and the secreting organ have been discussed.[420] It is easy to identify gender if both of these come from single organ, as the functional organ shows the dominant gender. On the other hand, if the person

[418] ʿAlī Ibn Muḥammad Al-Māwardī, vol. 11, p. 410.

[419] Al-Ḥaṭṭāb al-Ruʿīnī, Muḥammad ibn Muḥammad, *Mawāhib Al-Jalīl fī Sharḥ Mukhtaṣar Khalīl (The Majestic Gift of Compendium Partner)*, 3rd edn, vol. 6 (Dār al-Fikr, 1992), p. 425.

[420] ʿAlī Ibn Muḥammad Al-Māwardī, p. 383; ʿAbd Al-Mālik Al-Juwaynī, *Nihāyah Al-Maṭlab fī Dirāyah Al-Mazhab (Ending of the Questions in Realization of Juristic School of Thoughts)*, ed. by Maḥmūd ʿAbd Al-ʿAẓīm Al-Dayb (Saudi Arabia: Dār Al-Minhāj, 2007), p. 257.

experiences menarche through the female organ and ejaculation through the male organ, the person remains as *khunthā* due to equal probability.[421] A third means of gender assignment according to some other scholars is that if menses does not occur within the expected age, masculinity has been demonstrated.[422]

Fourthly, the growth of beard suggests a male gender. Next is pregnancy, which is considered as the absolute feature for a female. As a consequence of giving birth, all other features contradicting a female-line are rejected. The ability to impregnate someone is another evidence that the person is a man. Definitely this evidence should be observed in line with the Islamic rulings on two aspects: firstly, the conditions of legal marriage in Islam, and secondly, it does not apply for *khunthā mushkil* as marriage is prohibited for them until the dominant gender is ascertained. In case the issue of gender ambiguity is observed after the marriage, further investigation on the status of marriage should be conducted based on the rulings. The seventh and eighth features that manifest female gender are thelarche (breast development) and milk secretion. However, Al-Nawawī refutes milk secretion as a sign due to lack of evidence.[423] The ninth feature, i.e. the incipience of bravery and courage, indicates masculinity, although that would be challenged as a sign in the 21st century.

The tenth feature is of male or femaleness is insipired by the Ḥadīth on the creation of Ḥawwāʾ, who was created from the left rib of the Prophet Ādam.[424] Some scholars assume that there is a difference in the number of ribs between men and women.[425] This Ḥadīth was assumed to show that males having one extra rib on their left side, compared with the right. Whislt female has an equal number of ribs on both sides.[426]

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[421] ʿAlī Ibn Muḥammad Al-Māwardī, p. 383.

[422] Al-Suyūṭī, Jalāl al-Dīn ʿAbd al-Raḥman Ibn Abū Bakr, *Al-Ashbāh Wa Al-Naẓāʾir fī Qawāʿid Wa Furūʿ Fiqh Al-Shāfiʿiyyah (Plausible and Identical in Methodologies and their Branches of Shāfiʿī School of Thought)*, 1st edn, vol. 2 (Beirut: Dar al-Kutub al-`ʿIlmiyyah, 2001), p. 42.

[423] Muḥy Al-Dīn Al-Nawāwī, *Al-Majmūʿ Sharḥ Al-Muhazzab Li Al-Shirāzī*, ed. by Muḥammad Najīb Al-Muṭiʿī (Saudi Arabia: Maktabah al-Irshād, n.d.), p. 54.

[424] The Ḥadīth was reported by Abu Huraira: "Woman has been created from a rib and will in no way be straightened for you; so if you wish to benefit by her, benefit by her while crookedness remains in her. And if you attempt to straighten her, you will break her, and breaking her is divorcing her." Abu al-Ḥusayn Muslim ibn al-Ḥajjāj, *Ṣaḥīḥ Muslim (The Authentic of Muslim)*, ed. by Muḥammad Fuad ʿAbd al-Bāqī, vol. 2 (Beirut: Dār al-Kutub al-ʿIlmiyyah, 1991), p. 1091. Ḥadīth no. 1468, *Kitāb al-Radhāʿ* (Book Pertaining to Fosterage), *Bāb al-Waṣiyyah bi al-Nisāʾ* (Chapter Advice Regarding Women). Authentic Ḥadīth.

[425] Abū ʿAbd Allah Al-Qurṭubī, *Al-Jāmiʿ Li Aḥkām Al-Qurʾān (the Compiler for Qurʾanic Rulings)*, ed. by Aḥmad Al-Bardūnī and Ibrāhīm Aṭfīsh, 2nd edn, vol. 16 (Cairo: Dār al-Kutub al-Miṣriyyah, 1964), p. 52.

[426] Ibn ʿAṭiyyah, *Al-Muḥarrar Al-Wajīz fī Tafsīr Al-Kitāb Al-ʿAzīz* (Compendious Compilation in Expounding the Quran), vol. 2 (Beirut: Dār al-Kutub al-ʿIlmiyyah, 2001), p. 4.

Muḥsin al-Amīn al-ʿĀmilī, a Shiite scholar recorded that the fourth caliph (or the first Imam according to Shiism), ʿĀlī Ibn Abī Ṭālib once had been said to use this presumption to identify gender.[427] It happened during ʿĀlī's reign when a man was married to a *khunthā* and they were blessed with a child. Later, his wife had coitus with his maid and caused the maid to become pregnant. The *khunthā* had the physical and biological ability to be both a man and a woman. ʿĀlī, who was referred to, in order to solve the problem, then asked to count the *khunthā's* ribs. Due to an unequal number of the ribs, the *khunthā* was identified as male, assuming that one of men's ribs has been used in the creation of women. The marriage ended in divorce.[428]

Yet, this presumption about the number of ribs is invalid, according to Sunni and Shiite scholars. Al-Mawardi and Al-Nawawī refute this idea as there is no evidence in sharīʿah nor is there in anatomical basis for the understanding.[429] Similarly, al-Suyūtī also asserts that this characteristic has no valid connotation.[430] Al-ʿĀmilī mentions that the authenticity of the narrations is weak and contrary to the anatomists' views. According to Shiite jurisprudence, *khunthā's* gender is determined through the urination. Whenever both genitalia function simultaneously, a lot (*qurʿah*) can be cast to identify the gender.[431]

The last feature is with regard to psychological orientation in a state of incapacitating of other signs.[432] The psychological inclination towards man, with the person holds the opposite gender role, indicates femaleness and vice versa. These eleven features are the most common characteristics of males and females.

[427] Muḥsin al-Amīn Al-ʿĀmilī, *Aḥkām Amīr Al-Muʾminīn ʿAli Ibn Abī Ṯālib (Rulings of Amīr Al-Muʾminīn ʿAli Ibn Abī Ṯālib)*, ed. by Fāris Ḥassūn Karīm (Beirut: Markaz al-Ghadīr li al-Dirāsāt al-Islāmiyyah, 1998), pp. 104. -112.

[428] ʿAlī Ibn Muḥammad Al-Māwardī, vol. 9, p. 382.

[429] Muḥy Al-Dīn Al-Nawāwī, p. 54 ʿAlī Ibn Muḥammad Al-Māwardī, vol. 9, p. 382.

[430] Al-Suyūṭī, Jalāl al-Dīn ʿAbd al-Raḥman Ibn Abū Bakr, vol. 2, p. 41.

[431] Muḥsin al-Amīn Al-ʿĀmilī, p. 112.

[432] Al-Suyūṭī, Jalāl al-Dīn ʿAbd al-Raḥman Ibn Abū Bakr, vol. 2, p. 42.

4.3.6. Discussion on Methods of Assigning the Gender Proposed by the Jurists

Although in most other cases, the scholars would rely heavily on the Qurʾanic texts and Ḥadīth or be enlightened by the linguistic signs or the contexts, this is not the entire case in proposing gender assignment. The methodology of gender assignment proposed by the scholars is based on the historical context and their observations of human development. This does not mean that the interpretations are merely based on individuals' opinions. The researcher believes that it is the collective observations, eventhough not statistically recorded, over the centuries that has led to the methods used for deciding gender in ambiguous cases. The lack of textual evidence require them to do *ijtihād* based on *istiṣḥāb*, the presumption of common bodily development.[433] It should be noted also that their observations emphasize the biological and anatomical context. For example, when discussing the amount of the urine passed by a *khunthā*, Abū Ḥanīfah and Abū Yūsuf oppose this view on anatomical ground, i.e. the size of the bladder. In another instance, scholars oppose the number of ribs as a sign of gender differentiation for anatomical reason too. This shows that the scholars acknowledge the scientific evidence in supporting their arguments. Rispler-Chaim remarks that "the jurists' depth and creativity deserve nevertheless to be acknowledged".[434]

Comparisons of the classical views and current findings are made in order to identify the reliability of traditional opinions. We can divide it into two stages, i.e. infancy and puberty. During infancy, as discussed before, the urethra and the functioning organ play the role of identifying the gender. Anatomically, parts of the urinary system for both males and females are mostly the same and differ in several areas. We will not discuss in detail the differences, but it is sufficient to emphasize here the dissimilarities of the urethra's function and length for male and female. The urinary tract for males measures approximately 10 – 15 centimetres and serves as a pathway for semen and urine. However, a female's urethra is shorter at about 3 to 4 centimetres and functions

[433] *Istiṣḥāb* refers to the act of validating or refuting a matter in the present time or in the future based on the validation or refutation in the past due to the absence of evidence that change the original status. See further in Wahbah Al-Zuḥaylī, *Al-Wajīz Fī ʾUṣūl Al-Fiqh (A Compendium of Principles of Islamic Jurisprudence)* (Beirut: Dār al-Fikr, 1995) p. 115.

[434] Vardit Rispler-Chaim, *Disability in Islamic Law*, ed. by David N. Weisstub and Thomasine Kimbrough Kushner (Dordrecht: Springer Netherlands, 2006), p. 71.

only for urine excretion. It makes sense when the jurists assert that if a *khunthā* urinates by squirting it suggests that the person is a boy. Instead, if a person's urine flows by the thighs, this suggests a female.[435]

As Abū Ḥanīfah and Abū Yūsuf reject the recommendation of measuring the urine due to the different size of the bladder for males and females, the size differentiation is disproved by medical research. However, the refuting of the method is self-justified because the subject for gender assignment is the urethra and not the urine itself. Yazid Jalaludin, a Consultant Paediatrician and Paediatric Endocrinologist at the University of Malaya Medical Centre, Malaysia affirms that although there was no empirical evidence relied upon by the classical Muslim scholars, the assumption is helpful to guide medical practitioners in the first place to identify the correct gender.[436]

Though, relying upon this factor only is insufficient according to Muḥammad ʿAlī Al-Barr and Aḥmad Zuhayr al-Sibāʿī, especially for the condition with single ambiguous genitalia or with an orifice. For instance, a case was reported in Malaysia in 2012 in which the researcher herself became involved in a focus group discussion and conducted the research elsewhere.[437] 'BB' was brought up as female until she was 19 years old when she was referred to a hospital due to a tumour in her abdomen. The doctors found out that the tumour was initially her testis. That triggered the question of whether she was a male. From the diagnosis, she has 46,XY/45XO chromosomes. Among 60 blood cells, 46 cells showed 46XY chromosomes which is male and another 14 cells showed 45XO (a female partly missing an X chromosome). She was also identified as having a rudimentary male reproductive system and severe hypospadiac male external genital.[438] As we discussed in subtopic 3.4, Chapter 3, perineoscrotal hypospadias refers to a condition of urethra opening being at the perineum and forming vagina-like genitalia that masculinizes at puberty. There was no doubt for the midwife who delivered the girl when she was born. She firmly argued that the baby

[435] Aḥmad Ibn Al-Ḥusayn Al-Bayhaqī, vol. 6, p. 427. Ḥadīth No.: 12517.

[436] Yazid Jalaludin, *Telephone Conversation with Taqwa Zabidi,* (17 September 2016).

[437] Taqwa Zabidi, 'Hukum Penetapan Jantina Bagi Pesakit N.E.S (Rulings on Gender Assignment for N.E.S)', *Kertas Kerja Mesyuarat Panel Pakar Syariah Jabatan Kemajuan Islam Malaysia (Paperwork of Shariah Expert Panel Meeting, Department of Islamic Development Malaysia)*, vol. 86 (Putrajaya: 2014), 1 – 36, p. 6. The permission to use this data has been obtained from the Department of Islamic Development Malaysia. See Appendix A for further reference.

[438] Taqwa Zabidi, 2014, p. 3.

was a girl and not a boy. Apparently, an initial observation on the external part is insufficient. Other signs are necessary to support the argument of gender.

In modern terms, signs, as suggested by the jurists, are associated with sexual maturity and secondary sexual characteristics. Endocrinology explains puberty development. We will not go any further into the details of endocrinology. In short, it involves the pituitary gland (controlling hormones level generally), the hypothalamus (the part of the brain that controls the pituitary gland) and the gonads that contribute to pubertal development.[439] It is the view of Susman and others that pubertal development occurs earlier in girls than boys. Sexual development is observed in the changes that occur due to the brain factor. Although there are clear differences in the path of boys' and girls' brain development, it is not possible yet to identify whether a subject is male or female.[440]

Menarche and ejaculation have always been considered as indicators of tempo maturation, yet, current research shows they are a late event in the pubertal process.[441] At the onset of puberty, sexual maturation occurs. It can be seen in the internal and external development of a body, such as the development of testes and scrotum, growth of bodily hair, deepening of voice due to the growth of the larynx and prostate gland, in which, then, nocturnal ejaculation occurs.[442]

Variations of the order of the changes occur in girls. The development of breast or thelarche at the onset of puberty can be seen, and will develop in 5 stages as described by Tarner. The internal reproductive system will develop throughout the period and menstruation will occur at the end of the sequence after all hormonal changes have taken place.[443] Susman and others discovered through their longitudinal study that boys and girls reach sexual maturity at age 15½.[444]

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[439] Brian Bordini, Robert L. Rosenfield, Normal Pubertal Development: Part I: The Endocrine Basis of Puberty, *Pediatric in Review*, 32 (6) 2011, 223 -229, p. 224.

[440] National Research Council, *Adolescent Development and the Biology of Puberty-Summary of a Workshop on New Research*, ed. by Institute of Medicine, Michele D. Kipke and National Research Council (U.S.) Forum on Adolescence (Washington: National Academies Press, 1900), p. 13.

[441] National Research Council, p. 8; John C. Coleman, p. 30.

[442] John C. Coleman, p. 30.

[443] John C. Coleman, p. 30.

[444] Elizabeth J. Susman and others, 'Longitudinal Development of Secondary Sexual Characteristics in Girls and Boys between Ages 9 1/2 and 15 1/2', *Archives Pediatrics Adolescent Medicine,* 164 (2010), 166-173.

The elements of pregnancy and milk secretion for females and ability to cause pregnancy for males are those considered to be biological functions that can only happen after pubertal development and sexual maturation. Jurists accepted these as sufficient evidence to assign the gender because the gender role is obvious. A beard is another sign considered and categorized to show masculinity. Facial hair growth is associated with androgen, the hormone that stimulates and controls the body programme that governs male characteristics.[445] The congruity of hormones and facial hair growth depicts the maleness.

Psychological orientation is not discounted in this case although it is very subtle and subjective. Presently, there is large amount of data to associate the brain and hermaphroditism. Though, it needs to be stated here that in the Islamic perspectives, psychological orientation is only taken into account to identify gender after acknowledging such person is biologically facing gender ambiguity.[446] That is to say, this element alone is not considered to identify a person as *khunthā*. As discussed in previous chapter, the only Islamic mechanism to recognize a *khunthā* is through his/her ambiguous genitalia.

Overall, the signs of male and female suggested by the jurists before and during puberty are highly observed in their order and visible to the naked eye. Though, some of them lack of evidence and lost their ground. For example, the number of ribs is unjustifiable within anatomical knowledge for sex differentiation. In certain conditions, empirical evidence might help in producing a better interpretation of the Qurʾanic texts.

4.4. Evaluation of Gender Assignment Approaches From the Islamic Perspectives

We have been exposed to five major approaches in gender assignment. All these approaches have specific features that have their own weightage according to the core elements of their own field. The four major components involved are biological entities, social factors, cultural values and revelation texts. The issue here is how Islam views

[445] VA Randall, 'Androgens and Hair Growth', *Dermatologic Therapy*, 21 (Sept - Oct 2008), 314-328.
[446] Al-Suyūṭī, Jalāl al-Dīn ʿAbd al-Raḥman Ibn Abū Bakr, vol. 2, pp. 40-42.

these approaches. Could Islamic scholars accept and amalgamate all those views, or should they follow previous scholars' guidelines?

In balancing sacred texts, empirical research and live experiences, Islamic legal sources emphasize the use of cognitive capabilities. Several verses of the Qurʾān impel human to think, contemplate, cogitate, critically analyse and comprehend every creation in this world, not to mention the creation of sky, mountains, earth and animals. The most important issue to consider is the creation of humanity, i.e. ourselves. God emphasizes in the Holy Book, "As also in your own selves: Will ye not then see (and comprehend)?"[447] The deliberation of this verse is not limited but extends to understanding of the order of the biological process of human creation and its *dis-order*.

On the one hand, the Qurʾān itself wholly explains human creation. On the other hand, it continues to encourage further research and reminds "Therefore, do thou give admonition, for thou art one to admonish?"[448] It signifies that it is our duty to fill up the gap between the available information and those untold discoveries. The complexity of DSD often makes the indications of appropriate gender almost ambivalent. Again, the Qurʾān gives an example of how people can learn from the signs, directly or indirectly. Al-Ḥaṭṭāb al-Ruʿīnī (d. 954 AH/1547CE), a prominent scholar of the Mālikī school of thought, states that the method of seeking for critical assumptions is legally accepted in Islamic juridical thoughts.[449] The basis lies upon the Qurʾanic exegesis on the incident that happened to the Prophet Yūsuf where the ʿ*alāmāt* or indications suggested the actual situations.

The story narrated is full of wisdom. Prophet Yūsuf was seduced by his master's wife, known as Ra'eel or Zulaikha.[450] Prophet Yūsuf was accused of seducing Zulaikha. However, one of her household saw and bore witness, and said:

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[447] The translation of the Qurʾān, in ʿAbdullah Yūsuf ʿAlī, *Sūrah al-Zāriyāt* (The Winnowing Winds), 51: 21.

[448] The translation of the Qurʾān, in ʿAbdullah Yūsuf ʿAlī, *Sūrah al-Ghāshiyah* (The Overwhelming Pall), 88: 21.

[449] Al-Ḥaṭṭāb al-Ruʿīnī, Muḥammad ibn Muḥammad, p. 425.

[450] Asyiqin Ab Halim, 'Qurʾanic Stories in Introducing Messages and Values: An Analysis of the Story of Prophet Yusuf A.S.', *Jurnal Al-Tamaddun,* 11 (2016), 59-66, p. 62.

> "If it be that his shirt is rent from the front, then is her tale true, and he is a liar. But if it be that his shirt is torn from the back, then is she the liar, and he is telling the truth. So when he saw his shirt, -that was torn at the back, (her husband) said, "Behold! It is a snare of you woman! Truly, mighty is your snare!"[451]

Despite this particular incident, what is deducible from the story with regard to the technique of deducing is that these rulings are significant for comprehending related indications. This is the reason why the classical Muslim scholars listed the regular perceived signs of gender differentiation, conceivably due to limited knowledge and technology in that era.

Nonetheless, indications based on empirical research are more reliable compared to hypothetical signs. Valid argument and critical evidence are required to come to the conclusion, as mere assumption would increase the risks to the whole life of the patients. It is narrated by Qutaybah:

> "When he was with the Prophet and passed by some people who were tending the tops of their date palms. He asked, "What are these people doing?" (Some people) replied: "They are pollinating the trees by bringing the male parts into contact with the female parts." The Prophet said, "I do not think that this brings any benefit." They were informed on this and abandoned the practice. Then the Prophet was informed of their abandoning it and said, "If that will benefit them, then they should practice it. Indeed I only ventured a thought. Do not hold me to account for what I think. However, when I speak to you about anything regarding Allah, then accept it, for indeed I never speak falsely about Allah the Almighty.[452]

Based on this Ḥadīth, technology is welcomed for knowledge expansion and better living experiences that could only be gained through research and experiments, especially in terms of worldly matters. In another Ḥadīth, the Prophet admits that "You know best the affairs of your worldly life" referring to the experiment that the

[451] The translation of the Qurʾān, in ʿAbdullah Yūsufʿ Alī, *Sūrah Yūsuf* (Joseph), 12: 25-28.

[452] Abu al-Ḥusayn Muslim Al-Ḥajjāj, *Ṣaḥīḥ Muslim*, vol. 4, p. 1835. Ḥadīth no. 2361, *Kitāb al-Faḍāʾil* (Book Pertaining to the Excellent Qualities of the Prophet and Companions), *Bāb Wujūb Imtithāl Mā Qālah Sharʿa Dūn Mā Zakarah Min Maʿāyish al-Dunyā ʿAlā Sabīl al-Raʾy* (Chapter Obligation of Conformity with the Prophet's Sayings on Sharīʿah Excluding His Sayings on Worldly Matter). Authentic Ḥadīth.

Companions conducted.[453] Another similar Ḥadīth stresses the Prophet's nature as a human being, that might differ from God in giving opinions.[454]

The essence of these three *aḥādīth* includes, firstly, the Prophet's sayings regarding one's belief are mandated, while other matters are adaptable with the advancement of knowledge. Secondly, skills and experiences may enlighten people for better living. Thirdly, humans should progress themselves especially with regard to worldly affairs. Therefore, determinants of gender assignment should go concurrently between general guidelines from the Qurʾān and Ḥadīth, and current findings. The guidelines provided by the classical scholars may be revised and rectified, as aforementioned, then considered together with medical findings.

With regard to this discussion of using Islamic perspectives combined with scientific advance menthodology, there are three significant referential fatwas available. Firstly, one which was designated by *Al-Majmāʿ al-Fiqh al-Islāmī Rabiṭah al-ʿĀlam al-Islāmīy* (Islamic Fiqh Academy Muslim World League) in its 11th conference in Mecca on 26 February 1989, followed by the Council of Senior Scholars of Saudi Arabia in its 39th conference on 15 September 1992.[455] Thirdly, a similar decision was made by the General Presidency of Scholarly Research and Iftāʾ Saudi Arabia on 6 November 1999:

> "For those who have both male and female organs, the most dominant 'signs' should be considered. If there is more evidence leading to the male gender, then it is permissible to treat the person medically to eliminate the ambiguity of his gender. If there is more evidence leading towards the female gender, then it is permissible to treat the person medically to eliminate the ambiguity of her gender.[456]

[453] Abu al-Ḥusayn Muslim Al-Ḥajjāj, *Ṣaḥīḥ Muslim*, vol. 4, p. 1836. Ḥadīth no.: 2363, *Kitāb al-Faḍāʾil, Bāb Wujūb Imtithāl Mā Qālah Sharʿa Dūn Mā Zakarah Min Maʿāyish al-Dunyā ʿAlā Sabīl al-Raʾy*. Authentic Ḥadīth.

[454] Abu al-Ḥusayn Muslim Al-Ḥajjāj, *Ṣaḥīḥ Muslim*, vol. 4, p. 1835. Ḥadīth no.: 2362, *Kitāb al-Faḍāʾil, Bāb Wujūb Imtithāl Mā Qālah Sharʿa Dūn Mā Zakarah Min Maʿāyish al-Dunyā ʿAlā Sabīl al-Raʾy*. Authentic Ḥadīth.

[455] Islamic Fiqh Academy Muslim World League, *Majallah al-Majmaʿ al-Fiqh al-Islāmiy (Journal of Islamic Fiqh Academy)* vol. 8 (Mecca: al-Majmaʿ al-Fiqh al-Islāmiy, 2004), p. 341; Ṣāliḥ Fawzān Al-Fawzān, *Al-Fatāwā Al-Mutaʿalliqah Bi Al-Ṭibb Wa Aḥkām Al-Marḍā (Verdicts in Relation to Medicine and Rulings on Patients)* (Riyadh: Riʾāsah Idārah al-Buḥuth al-ʿIlmiyyah wa al-Iftāʾ, 1424H), p. 306.

[456] General Presidency of Scholarly Research and Iftāʾ, *Fatāwā Al-Lujnah Al-Dāʾimah (Fatwa of General Presidency)*, ed. by Aḥmad ʿAbd Al-Razāq Al-Duwaish, (Riyadh: Riʾāsah Idārah al-Buḥūth al-ʿIlmiyyah wa al-Iftāʾ, n.d.), p. 49.

Council Senior Scholars add that "[i]t is either hormonal or surgical treatment because it will provide the benefit and impede the detriment."[457] Further elaboration on the treatment will be provided in Chapter 5. At this point of view, it is clearly shown that members of the three councils agree that all dominant signs that depict either maleness or femaleness should be referred to, in order to assign the gender for *khunthā wāḍiḥ* (discernible). Instead, if there are no dominant signs to confirm either the masculinity or femininity of such people, they will remain as *khunthā mushkil* (intractable).

These fatwas have been referred to by practitioners such as Jurayyan, a paediatrician in Saudi Arabia; Mohd Salim, a senior lecturer in Malaysia; and Ani Amelia, a consultant and paediatrician in Malaysia, in seeking to understand the issue from Islamic perspectives.[458] However, the generality of the word 'signs' can be understood as including both the genetic and the physical make up of a person. Dessouky enquired from religious experts on what is defined by the word *al-ʿalāmāt* or 'signs' whether it includes the chromosomal sex, the gonadal sex, the phenotype, and the appearance and function capability of external genitalia.[459]

To date, juristic councils have provided no answer to that question, leaving them for the doctors to decide. Al-Barr, a medical consultant in King Fahd Centre for Medical Research is in favour of this approach. He presented a paper in the World Muslim League Islamic Fiqh Academy clarifying that the doctors have the ability to assign the gender based on the chromosomal and gonadal factors and that afterwards religious scholars could deal with the patients in terms of juridical rulings based on the medical recommendations.[460] For Syed Sikandar Shah Haneef, an expert of Islamic law in Malaysia, even seeking assistance from the medical experts is useful as the jurist-

[457] Ṣāliḥ Fawzān Al-Fawzān, p. 306.

[458] Nasir A. M. Al-Jurayyan, 'Disorders of Sex Development: Diagnostic Approaches and Management Options - an Islamic Perspective', *Malaysian Journal Medical Science*, 18 (Jul - Sep 2011), 4-12; Mohd Salim Mohamed and Siti Nurani Mohd Noor, 'Boy or Girl: A Malaysian Religious and Ethical Approach', *Revista Română De Bioetică,* 12 (2014), 136-144; Ani Amelia Zainuddin and Zaleha Abdullah Mahdy, 'The Islamic Perspectives of Gender-Related Issues in the Management of Patients with Disorders of Sex Development', *Archives of Sexual Behavior,* (21 April 2016), 1-8.

[459] Nabil M. Dessouky, p. 499.

[460] Zuhayr Aḥmad Al-Sibāʿī and Muḥammad ʿAli Al-Barr, *Al-Ṭabīb Adabuh Wa Fiqhuh (Ethics of Physician and its Jurisprudence)* (Damascus: Dār al-Qalam, 1993), p. 316.

consults themselves should be acquainted with the cause of rulings, known as *taḥqīq al-manāṭ* in the principle of Islamic jurisprudence.[461]

A similar formula in ascertaining the cause of a ruling or *ʿillah,* as presented in the previous chapter is applicable for the purpose of identifying the determinants of gender assignment. The features of *ʿillah* can be considered as being appropriate, visible, constant and transferable. Where there are indications that fit into all these features, an Islamic legal ruling can be reached. The indications should fit into these features to enable the process of ascertaining the 'correct' gender.

Firstly, the indication should be appropriate and not a mere assumption. It is mentioned in the Qurʾān, "…truly suspicion can be of no avail against truth. Verily Allah is well aware of all that they do".[462] This Qurʾanic verse inspires one of the five major principles of legal maxims namely 'certainty is not dispelled by doubt' (*al-yaqīn lā yuzāl bi al-shak*). In medical diagnoses, it is not always possible to attain a degree of the truth (*al-yaqīn*). Existing and established policies are regarded perfect probabilities, although working diagnoses are prone to changes and refinement from time to time. Hence, clinical diagnoses should not be undermined when it comes to gender assignment, leaving the favourable gender as an option without a valid argument.

The 'principle of certainty' should also be read together with another legal maxim known as 'the original ruling of matters related to genitalia is prohibition' (*al-aṣl fī al-abḍāʿ al-taḥrīm*).[463] Therefore, all actions related to sexual function, including but not limited to sex assignment, sex surgical procedure, imposing gender role and behaviour, are forbidden until there is concrete evidence to prove the need of it.

Secondly, the determinant of gender assignment should be visible and able to be evaluated. For example, based on chromosomal and hormonal tests, the karyotype reading and level of hormone is apparent. Knowledge of human sexual development permits the medical experts to understand gender differentiation. The facets of

[461] Sayed S. Haneef and Mahmood Zuhdi Abdul Majid, 'Medical Management of Infant Intersex: The Juridico-Ethical Dilemma of Contemporary Islamic Legal Response', *Zygon: Journal of Religion & Science*, 50 (December 2015), 809-829, p. 826.

[462] The translation of the Qurʾān, in ʿAbdullah Yūsuf ʿAlī, *Sūrah Yūnus* (Jonah), 12: 36.

[463] Al-Suyūṭī, Jalāl al-Dīn ʿAbd al-Raḥman Ibn Abū Bakr, vol. 1, p. 61.

differentiation signify the indications that will suggest the path of sexual development to be taken by such patients whether on female or male-line development. Psychosexual orientation is a debatable component which borders the permissiblity and prohibition.

The third Islamic feature to be considered in ascertaining gender is consistency and stability. The indications which are not stable, or change or vary from time to time or from one circumstance to another, are discounted. For example, the form of reproductive organ which is penetrable via current technology, is a constant and firm indication. Societal perception and environmental effect do not fit with this feature as they are volatile and vary due to a number of factors, including culture and religion.

The fourth feature is that the symptoms are common and transferable. That is to say, the existence of nonexistence of determinants are generally applicable or available in all conditions. It cannot be a specific or exclusive indication for certain conditions only. For example, gonadal sex hormones stimulated by testosterone suggests male development and its absence leads to female production.[464] On the other hand, favourable gender is subjective across societies. For instance, Chinese and Middle Eastern societies favour the male gender, while Malays have proven to have no preference.[465] Hence, preference is not fit to be a determinant due to its unstable features.

The Shāfiʿī school of thought proposes three steps to determine the basis of Islamic rulings. Firstly, is to extract the cause of the rulings, known as *takhrīj al-manāṭ*. In this sense, once a *khunthā* is identified based on all the internal and external features discussed in the previous chapter, diagnosis takes place. All information is gathered, including clinical findings and the history and background of the patient and his or her family.

The next step is *tanqīh al-manāṭ*. This is the phase in which the information of a case is analysed and tested. Only related indications that comply with the features of the

[464] Daniel W. Leger, *Biological Foundation of Behaviour: An Integrative Approach* (New York: Harper Collins Publisher, 1992), p. 221.
[465] Ursula Kuhnle and Wolfgang Krahl, p. 94; Nasir A. M. Al-Jurayyan, p. 4.

cause of ruling are chosen. Finally is the determination of *ʿillah*. This step is known as *taḥqīq al-manāṭ*. Subsequently, the determination of rulings, i.e. the gender assignment can be performed. Nonetheless, this determination is not straightforward. Making a decision requires an agreement of all related parties. A such decision on one's gender comes together with a bundle of risks that can effect the rest of one's life. Different backgrounds, beliefs, and cultures among groups of decision makers lead to different decisions. This issue will be analysed thoroughly in Chapter 6 on the Decision Making Process.

To sum up Islam's views on all approaches of gender assignment, it is clear that relying on one approach is insufficient. This is because:

a. Clinical policy emphasizes biological make up including phenotype and genotype factors. There are a few identified clinical determinants for gender assignment purposes, but none is assumed more dominant than others. Hence, a lack of other supporting factors such as psychosexual orientations may lead to a different sex rearing of a child.
b. The Social Model's beliefs on the societal and environmental factors disregards the importance of biological entities which internally contribute to the development of an individual.
c. The Biosocial Model, a refined and improved theory of social and clinical approaches, suggests a wider perspective. However, it is reported that factors other than medical recommendations may have greater influence over decision making process.
d. The cultural approach provides unstable and inconsistent determinants of gender assignment. In certain circumstances, the interests of parents are given priority over and above the child's welfare or interests.[466] But it may cause a negative long-term impact if the 'true gender' is not revealed from the ambiguous one. It is appropriate to recognize that good medical decisions are profound in the determining of the real sex biologically rather than based on cultural understandings.[467] This preference for science over cultural is parallel with what we have understood from the previous chapter on gender assignment

[466] Mohd Salim Mohamed and Siti Nurani Mohd Noor, 'Boy or Girl: A Malaysian Religious and Ethical Approach', *Revista Română De Bioetică,* 12 (2014), 136-144, p. 137.
[467] Suzanne J. Kessler, p. 10.

that supports the guidelines in the sharīʿah. *Islamic* cultural factors, as perceived by certain groups of Muslims, may not guarantee lifelong sex rearing without sex reassignment.

e. Culture is represented by custom and 'custom is the basis of judgment' (*al-ʿādah al-muḥakkamah*) as pointed in the Islamic legal maxim. However, custom which is legally uphold in Islamic law is the one that is not in conflict with the principles of sharīʿah. Even, both, men and women, are equal in the eyes of God.[468] It shows that mere cultural preference factor is in contrast with Islamic spirit.
f. The classical Islamic approach, on the other hand, is a hypothetical and observational approach in proposing the determinants of gender assignment. Although most of the guidelines are parallel with biological differentiation theory, they are limited to visible elements only.

4.5. Towards a New Holistic Approach of Gender Assignment – A Proposal

Hence, the researcher proposes a new model of gender assignment that holistically accommodates all required elements and determinants. The notion of Islamic bioethics, as has been discussed in Chapter 2 underlies this model which encompasses three characteristics as below:

i. Based on Islamic moral and legislative sources.
ii. Methodology for defining, analysing and resolving ethical issues based on the principles of Islamic jurisprudence and Islamic legal maxims.
iii. Aim at achieving the goals of *maqāṣid al-sharīʿah*.

This approach is a perpetuation of previous related discussions on *khunūthah* and DSD. Prior to gender assignment, the status of individuals with gender ambiguity should be clearly understood, ascertaining the occurance of a disorder of sexual development. Inevitably, other conditions including Gender Dysphoria without DSD as described by the Diagnostic and Statistical Manual of Mental Disorders (DSM) 5 are

[468] The basis can be found in *Sūrah al-Naḥl* (The Bee), 16: 97 when Allah mentions, as it is translated, "Whoever works righteousness, man or woman, and has Faith, verily, to him will We give a new Life, a life that is good and pure and We will bestow on such their reward according to the best of their actions." Another verse of the Qurʾān is in *Sūrah Āli ʿImrān,* 3: 195, as can be understood from the translation, "…Never will I suffer to be lost the work of any of you, be he male or female: Ye are members, one of another…"

excluded from this approach of assigning such gender.[469] Although Heino Meyer-Bahlburg, a psychologist specializing in DSD and a member of the working group of DSM 5, mentions the query of acknowledging atypical brain structures which lead to Gender Identity Disorder as intersexuality; that will not change the conceptual scope of ascertaining a person with sex ambiguity in Islam.[470] The reason is based on the Qurʾān and Ḥadīth being immutable evidence that prohibit alteration of Allah's creation even when effiminacy in communication, acts and physical appearance are present.[471]

The basis of the newly proposed approach relies upon Islamic moral and legislative sources. Although there is no specific evidence from the Qurʾān and Ḥadīth on how gender ambiguity could be resolved, the Qurʾān does promote manipulation of empirical evidences and technological advancement to achieve better quality of life. Hence, clinical determinants other than attribution to the urinary tract (*ḥukm al-mabāl*) not only could; but should be referred to in determining the gender of an affected person. Asrorun Ni'am Sholeh, Secretary to Fatwa Commission, the Council of Indonesian Scholars said:

> "Based on Islamic legal ruling, if there is sex ambiguity occurs, it should be clarified. The most dominant indicator should be considered first. How it should be done? It must relate to medical perspective… If there is no dominant indicator from the Islamic perspective, the most dominant clinical indicator should be sought to identify the gender, either male or female."[472]

Most medical literature confirms both genotype and phenotype signs as able to identify a dominant gender. Consequently, the phenotype elements can be classed as an 'observable sign' as permitted and reccommended by the classical Muslim scholars. Remember, as aforementioned, the number of ribs as an observable sign of gender has been refuted by many Shāfiʿi's scholars. This strongly affirms the significance of the proposed redefined version of *khunūthah,* as to include the association of chromosomal and gonadal factors in the case of ambiguous genitalia.

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[469] DSM 5 is a clinical guidebook for assessment and diagnosis for mental disorder published by American Psychiatric Association. It is a refined edition of DSM-IV. See American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders*, 5th edn (Arlington, VA: American Psychiatric Association, 2013).

[470] Heino F. L. Meyer-Bahlburg, 'Commentary on Kraus' (2015) "Classifying Intersex in DSM-5: Critical Reflections on Gender Dysphoria", *Archives of Sexual Behavior,* 44 (2015), 1740.

[471] See *Sūrah al-Al-Nisāʾ* (The Women), verse 119; See also Ḥadīth related by Abu al-Ḥusayn Muslim Al-Ḥajjāj, *Ṣaḥīḥ Muslim*, vol. 3, p. 1676. Ḥadīth no. 115, *Kitāb al-Libās wa al-Zīnah* (Book of Attire and Adornment).

[472] Asrorun Ni'am Sholeh, *Conversation with Taqwa Zabidi* (25 September 2017).

It is worth reiterating here that psychosexual orientation is not applicable to identify a person as intersex or *khunthā* at the very beginning phase.[473] But, it is recognized as one of the final determinants in Sunni schools of thought when deciding gender assignment, and when other signs are deemed as feeble or weak. Likewise, Cynthia Kraus highlights Meyer-Bahlburg's opinion, in the review of classifying DSD in DSM 5, that clinical diagnosis, using Kraus's words, is the "first-order" followed by gender dysphoria diagnosis as the "second-order" for patients with DSD.[474] The importance of this priority will be shown in later discussion.

Cultural and other environmental forces may have great influence on gender assignment as proposed by the Social Model.[475] These forces, in the researcher's view, are not intrinsic evidences, rather, the influential factors in making a decision. Though, consideration must be made of these factors by utilising *al-maṣlaḥah al-mursalah* (unregulated interest), a juristic mechanism to achieve *maqāṣid al-sharīʿah* (the objectives of sharīʿah). To recap the discussion in Chapter 2, safeguarding and protecting life, mind and offspring are among five principles of the objectives of sharīʿah which are closely related in managing patients with DSD and *khunthā.* Reference also being made to Islamic legal maxims on removing harms and eliminating preponderant impairment in those cases. Respecting those legal maxims will guide and guard appropriate consideration of those elements in order to ensure the fulfilment of public interests and avoidance of mischief. Further discussions will show the technique of utilising this approach in determining gender for *khunūthah* and patients with DSD.

Based on the classification of DSD and *khunūthah* as proposed in Chapter 3, Table 3 sums up Islamic biomedical approach on gender assginment for patients with DSD, as a new proposal.

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[473] Islamic Expert 2, *Telephone Conversation with Taqwa Zabidi* (21 January 2016); Mohd Kashim, Mohd Izhar Ariff, *Telephone Conversation with Taqwa Zabidi,* (13 January 2016); Islamic Expert 1, *Conversation with Taqwa Zabidi*, (27 August 2015).

[474] Cynthia Kraus, 'Classifying Intersex in DSM 5: Critical Reflections on Gender Dysphoria', *Archives of Sexual Behavior,* (2015), p. 10.

[475] A. D. Fisher and others, p. 1215.

Table 3: Gender Assignment According to the Types of Khunūthah Cases and Its Implication

Types	Gender Assignment	Implication on Religious Obligations
Khunthā Wāḍiḥ **(Discernible *khunthā*)**	Gender is identified based on the Islamic biomedical approach.	The person is subject to *fiqh* of *khunūthah* until the dominant gender is ascertained. As soon as the gender is determined, the person is subject to the rules according to the assigned gender.
Khunthā Mushkil **(Intractable *khunthā*)**	Gender determination is perceived impossible. The evaluation could be carried out from time to time, if there are any biological or physical changes.	The person is subject to *fiqh* of *khunūthah* until the dominant gender is ascertained. Then the person will be subject to the rules according to the assigned gender.
Non-*khunūthah* (Other types of DSD)	Gender remains as what was assigned at birth unless gender reassginment is required immediately. The Islamic biomedical approach is used in the latter case for the correct-sex determination.	The person is subject to the rulings according to the (re)assigned gender. *Fiqh* of *khunūthah* is not applicable in this case.

4.5.1. Islamic Biomedical Approach in Resolving Gender Ambiguity of *Khunūthah*

In the proposed new method for Islamic Biomedical approach, both genotype and phenotype elements should be considered in identifying the dominant gender. This step is analysed during the process conducted by the Department of Islamic Development Malaysia, also known as JAKIM (an acronym of Malay: *Jabatan Kemajuan Islam Malaysia*). JAKIM, as will be explained in Chapter 7, is one of 58 departments under the Prime Minister's Department of Malaysia and ensures the efficiency and effectiveness of the management of Islamic affairs.[476] Its role is coordinating Islamic affairs among the 14 States of Malaysia at the federal level as Islamic affairs, constitutionally, fall under the jurisdiction of the states. More often than not, critical issues are referred to Research and Planning Division, JAKIM, where the researcher herself was employed. Under this Division, Shariah Expert Panel (*Panel Pakar Syariah* or previously known as Shariah Research Panel) was established since 1990 to discuss various matters that require Islamic rulings' underpinnings. Further

[476] Jabatan Kemajuan Islam Malaysia, *Jakim 4 Dekad Memacu Transformasi Pengurusan Hal Ehwal Islam*, ed. by Mohamad Saari (Putrajaya: Jabatan Kemajuan Islam Malaysia, 2012), p. 2.

description on Shariah Expert Panel can be found in subtopic 7.3.1, Chapter 7 on Islam and Its Administration in Malaysia.

Amongst the hundreds of issues discussed by the Panel, issues on *khunūthāh* and related matters have been discussed since 2000. The discussion started with general points on sex change and sex identity in identification cards. It went to a narrower scope in 2006 on two types of DSD focusing on assignment and reassignment of gender. Research was conducted based on the data collected from Ministry of Health Malaysia without the involvement of patients. The results of all these discussions were deliberated at the national level the meetings of Fatwa Committee for National Council of Islamic Religious Affairs Malaysia. The same results have been made public.

A more specific discussion on individual cases was first referred to JAKIM in 2010. This sparked intense attention of the Panel, as it directly involved a patient's future. List of cases could be found in Chapter 7. One of the examples is the case was that of BB, a girl with an abdominal tumour. She was diagnosed with 46XY/45XO chromosomes. Among 60 blood cells, 46 cells showed 46XY chromosomes which indicates maleness and another 14 cells showed 45XO (a female identification but partly missing an X chromosome). She was also identified as having a hymen-alike opening below the dislocated urethra opening of the penis. After the treatment, she had no male or female reproductive system. She was given hormonal treatment to prevent any health risks in the future, which indirectly maintained higher levels of female hormone, i.e. estradiol, compared to testosterone, a male hormone.[477]

The important point needed to make here is how the analysis of gender assignment was made. Both Islamic and medical perspectives were reviewed for BB's case through semi-structured interviews with six medical experts from different backgrounds of expertise, including a geneticist, a surgeon, an andrologist, a paediatrician, a gynaecologist, and a psychiatrist. Secondly, literature research on Islamic perspective was conducted and analysed, utilizing the principles of Islamic

[477] Taqwa Zabidi, *Hukum Penetapan Jantina Bagi Pesakit N.E.S (Rulings on Gender Assignment for N.E.S)*, pp. 12 – 17.

jurisprudence (*uṣūl al-fiqh*) in which contemplation on proofs of injunction (*adillah al-aḥkām*) were used in a systematic approach.[478]

The status of the patient was presented, including chromosomes, hormones, the reproductive organs and external genitalia, physical appearance and psychological orientation. To analyse the data, two matrix tables, as in Table 4 and 5, have been created by the researcher, listing the information based on the determinants of gender assignment from the Islamic and medical approaches. The main objective of inventing this matrix table was to ensure consideration of all aspects of gender determinants without missing any, which is especially important for delicate cases. Additionally, the tables may be the best tool for decision making process when considering multiple factors.

Both tables show the signs of females and males from the Islamic and medical perspectives, respectively. In Islam, the sign of inclination is recognised as weak because of its fluctuating nature emotionally. While the existence of penis indicated the male gender, it did not properly function due to permanent inability to ejaculate. Following this analysis, socio-psychological development was evaluated. The panels then focused on the purpose of achieving benefits and avoidance of harms (*al-ḍarār*). As al-Ghazali points out, eliminating harms is part of achieving benefits, the panels also analysed the various degree of harms and considered the lesser level, guided by the Islamic legal maxims, i.e. ‘a greater harm is eliminated by means of a lesser harm’. It had been demonstrated that the risks of bringing up the girl as a girl were lesser than reassignment to male. Her psychological orientation was unwavering female. Despite being incapable of pregnancy, she may perform marital intercourse as a female due to the existence of an opening. Reassigning her to be male might lead to a stressful life of new, changing surroundings in which she would be incapabe of the male sexual function.

[478] Taqwa Zabidi, *Hukum Penetapan Jantina Bagi Pesakit N.E.S (Rulings on Gender Assignment for N.E.S)*, p. 28 – 33.

Table 4: Analysis 1 on BB's Status from the Islamic Biomedical Approach

Status Sex	Islamic-approach Signs	Patient's Status	
	Genitalia	Male genitalia developed at later age.	/
Male	Beard	No beard	x
	Ejaculation	No	x
	Psychosexual orientation (Interested in women)	No	x
Female	Genitalia	Urine excreted from an opening resembled vagina-like at early age.	/
	Thelarche	Flat	x
	Menarche	No due to absence of ovaries.	X
	Milk secretion	No	x
	Ribs	No related info	x
	Psychosexual orientation (Interested in men)	Yes	/

Table 5: Analysis 2 on BB's Status from the Islamic Biomedical Approach

Sex Elements		Male	Female
Genotype		XY and XO	
Phenotype	Gonads	1 testicle has been removed and the other of the pair is missing.	No ovaries.
	Genitalia	Yes with hypospadias.	No female genitalia but has an opening.
	Secondary sexual development	No beard and moustache.	No breasts.
	Hormones	Testosterone decreased after hormonal treatment.	Oestrogen increased after the consumption.

This is one example of the method used for analysing the data. The matrix table does contain all required information, is balanced between the two perspectives, and suggests the 'suitable' gender. In most cases, the table indicates the dominant gender for the patient. This technique has been applied for all other DSD cases and the table has been improved from time to time as in Table 6 for patient 'EE'.[479] EE is an active teenager and a national Malaysian athlete. EE was assigned as female and had had

[479] Taqwa Zabidi, *Hukum Penetapan Jantina Bagi Pesakit N.A.R (Rulings on Gender Assignment for N.A.R),* Kertas Kerja Mesyuarat Panel Pakar Syariah Jabatan Kemajuan Islam Malaysia (Paperwork of Shariah Expert Panel Meeting, Department of Islamic Development Malaysia), vol. 98 (Putrajaya: 2017), 1 – 22, p. 18.

inguinal hernia at the age of 1 year. At her age of 15 year, her genitalia became virilised. Her pubertal development was that of male's, such as developing a deep voice, a male physique with hirutism, sexual attraction to women, in male role. Her breast did not develop like any other girls at her age. Her cognitive status was also analysed by a psychiatarist and proven was in a stable and normal condition without any depression sign. The panel was statisfied with the hospital's recommendation for EE's gender reassignment as male.

The decision was made, partly based on the data presented as in Table 6. Despite the use of two tables, the data was gathered and rearranged in one table. The researcher argues that the matrix table could help medical practitioners to evaluate cases of Muslim patients with DSD. Apparently, this tool supports determination of gender in almost all cases and simultaneously minimizes the number of cases of *khunthā mushkil*.[480] In the case of weak existence of a dominant gender, the patient remains as *khunthā* until the clear signs manifest themselves. As a consequence, cases of *khunthā wāḍiḥ* whose gender is identified thereafter are excluded from the fiqh of *khunūthah*. While *khunthā mushkil* remain to its rulings, so long as the gender is not ascertained.[481]

Table 6: Analysis of EE's Status from the Islamic Biomedical Approach

	Features	**Patient's Status**	**Male/female line**
Islamic Perspective	Genitalia	Resemble vagina	Female
		Penis (during puberty)	Male
	Ejaculation	No	
	Growth of beard	Mustache and beard	Male
	Menses	No	
	Thelarche	No	
	Milk secretion	No	
	Sexual orientation	Towards female	Male

[480] This approach has been presented by the researcher in Paediatric and Adolescent Gyneacology Conference 2019 hosted by Chancellor Tuanku Muhriz Hospital, the National University of Malaysia on 21 and 22 September 2019.

[481] Islamic Expert 2, *Telephone Conversation with Taqwa Zabidi*, (21 January 2016).

	Features	Patient's Status	Male/female line
Medical Perspective	External Genitalia	Penis (6.6 cm with perineoscrotal hypospadias & no seminal vesicle)	Male
	Gonad	Testis (right: 8 – 10 mls; left: 8mls)	Male
	Chromosome	46XY	Male
	Hormone	Testosterone: 22.8 nmol/L (before test) 40.2 nmol/L (after test) High DHT	Male
	Secondary sexual characteristics	Deeper voice Mustache Beard Wide chest	Male
Psychological and Psychosocial Analysis of Benefits and Harms			
Maṣlaḥah* and *mafsadah	Fertility & reproduction	Understand the implications. Willing to undergo the treatment.	*Maṣlaḥah* prevail.
	Family and friends	Family welcomes the new status. Ready to face the challenges.	
	Change of gender status in the identification of card.	Understand the process and procedure of changing the gender status.	

4.5.2. Islamic Biomedical Approach in Resolving Gender Ambiguity for Patients with DSD

A question is raised whether this Islamic Biomedical approach could resolve the major conditions of those who are facing DSD in general? What happens for those who retain normal male or female genitalia that contradicts with gonads and/or sex chromosomes? What happens to those who have incomplete development of genitalia which is in line with the gonads and sex chromosomes?

In Islam, medical treatment is recommended based on a Ḥadīth narrated by Muslim which encourages people to seek for treatment.[482] Therefore, those who are not *khunthā* are eligible to receive any treatment whether, firstly, to align the genitalia with the gonads and chromosomes or secondly, to make corrective surgery for the

[482] See Ibn Mājah, Muḥammad Ibn Yazīd, *Sunan Ibn Mājah*, ed. by Farīq Bayt al-Afkār al-Dawliyyah, 2nd edn (Saudi Arabia: Bayt al-Afkār al-Dawliyyah, 1999), p. 372. Ḥadīth no.: 3436, *Kitāb al-Ṭibb, Bāb Ma Anzal Allah Dāʾ Illa Anzal Lah Shifāʾ* (Book Medicine, Chapter Allah will not send down disease except He send with it remedy). Authentic Ḥadīth.

genitalia. In both cases the patients are not regarded as *khunthā* and therefore Muslim patients are not obliged to refer to Islamic rulings for *khunthā.* The issue of DSD is, how gender can be determined. Cases of the latter example above need no gender assignment due to their clarity of gender. For example, hypospadias and micropenis problems among boys require corrective surgery to ensure the opening of urethra is located at its appropriate place.

However, the former case entail determination of gender whenever the chromosomes and gonads are found discordant with *normal* external genitalia. It can be divided into two general conditions, i.e. DSD patients born with typical female external genitalia and DSD patients born with typical male genitalia. In his extnesive research on Gender Identity Differentiation (GID), Zucker concludes that "GID occurs in individuals who are unambiguously assigned at birth to the male or female sex."[483] This is what Dessouky coins as "sex missassignment" when there is discordant between the genotype and the sex of rearing.[484] Some medical literature suggests management of gender assignment for these conditions, according to their various factors of differentiation. The first condition includes, for instances, patients with Complete Androgen Insensitivity Syndrome (CAIS) and 5-α Reductase 2 Deficiency. The type of these DSD may confuse readers on what they are all about. But further examples will enlighten us on how the request for sex change for those who born with typical genitalia at birth should be considered.

A.D. Fisher and others reviewed numbers of relevant literature and provided recommendations in managing these types of DSD.[485] In 46,XY individuals with CAIS, the genitalia appears to be of typical female type. However, as explained in Chapter 3, secretion of Anti-Müllerian Hormone by the testes leads to distortion of the development of internal male genitalia. It has been suggested that patients with CAIS should be reared as female because:

a. They have unwavering female typical gender identity, gender role behaviour and sexual orientation towards male.

[483] Kenneth J. Zucker, 'Intersexuality and Gender Identity Differentiation', *Annual Review of Sex Research,* 10 (1999), p. 39.
[484] Nabil M. Dessouky, 'Gender Assignment for Children with Intersex Problems: An Egyptian Perspective', *Egyptian Journal of Surgery,* 20 (April 2001), 512.
[485] A. D. Fisher and others, p. 1207.

b. Corrective surgery for the external genitalia to be consistent with female gender is unnecessary.
c. Although hormonal treatment with oestrogen is required after removal of the testis (gonadectomy), androgen insensitivity makes the testosterone replacement weak.

Conversely, individuals with 5-α reductase deficiency who possess female external genitalia at birth – although some of them present with ambiguous genitalia – also normally own male signs such as undecsended testis and wolfian ducts and ejaculatory ducts. Patients are normally assigned as female at birth. However, at puberty, a gender role change from female to male is reported due to variable degree of exposure to androgens. Two young Malaysian athletes were reported to have this type of DSD.[486] They were initially involved in women's games but later transferred to male games after asking for gender reassignment. Fisher and others recommend that patients are assigned as male, despite female genitalia because:[487]

a. There is high percentage of gender reassignment request after puberty, with fertility potential.
b. Genital tissue is responsive to androgen, even though genitalia may not completely appear as male anatomy after the treatment.
c. Hormonal treatment is unnecessary if the testes are not removed.

These recommendations – including other recommendations – are helpful as the guidelines for related medical practitioners in general. However, this theory is a general guideline, in which the case might differ from one to another. It also should come with a proper analytical tool to cater for non-medical factors that may influence the final decision. Realizing this need, the Islamic biomedical approach presented its analysing matrix table. It might, as proposed, provide a better methodology for assesing gender assignment.

[486] Taqwa Zabidi, *Hukum Penetapan Jantina Bagi Pesakit N.E.S (Rulings on Gender Assignment for N.E.S);* Taqwa Zabidi, *Hukum Penetapan Jantina Bagi Pesakit N.A.R (Rulings on Gender Assignment for N.A.R),* Kertas Kerja Mesyuarat Panel Pakar Syariah Jabatan Kemajuan Islam Malaysia (Paperwork of Shariah Expert Panel Meeting, Department of Islamic Development Malaysia), vol. 98 (Putrajaya: 2018).
[487] A. D. Fisher and others, p. 1207.

4.6. Conclusion

Gender assignment is one of the most debatable issue in managing patients with DSD. There are several approaches on gender assignment – excluding theories on gender development – as what have been presented in an earlier chapter. Every approach has its own ground and focuses to achieve, thus limiting its capability to consider various factors in assigning the 'correct' gender. Hence, another approach relying upon Islamic biomedical ethics has been introduced. To analyse the determinants in seeking for the dominant gender, biological signs are recorded together with apparent determinants as proposed by the classical Muslim scholars. Other non-medical factors are then analysed through juristic mechanisms to achieve the objectives of sharīʿah.

5. TREATMENT OF PATIENTS WITH DSD

5.1. Overview

The most contentious issue in managing patients with DSD is with regard to treatment. In fact, the first aspect that comes to mind when discussing ambiguous genitalia is sex surgery. This chapter will analyse the second research objective, calling for Islamic bioethical underpinnings on medical intervention for patients with DSD. To begin the discussion, it is important to understand the significance of treatment of gender ambiguity for Islamic and medical purposes. This is followed by an exploration of surgical and hormonal treatments in order to understand the types of treatments and to what extent these treatments are essential. General types of available treatments will be introduced to highlight four ethical issues encountered by patients and families for further investigation. Subsequently, this chapter evaluates the Islamic ethos in two contexts, namely Islamic rulings on medical interventions on patients with DSD and proposed alternative to curtail any ethical issues, especially the postponement of surgical interventions. The latter is achieved by employing *maṣlaḥah* as a measuring control with a condition of thoroughly apprehend the types of the treatment and suitable choices depending on the cases. The end of this chapter summarizes the Islamic perspectives on treatments as a whole in relation to the three categories of patients with DSD and *khunthā.*

5.2. The Importance of Treatment for Religious and Medical Purposes

The goal of gender assignment is to accommodate the requirement of performing gender-related religious obligations and eventually to assist the affected person to interact socially like any other person. Religious obligations (ʿ*ibādah*) retain the wisdom associated with individual wellbeing and goodness and contribute to societal reconciliation. According to Sachedina, four areas of an individual's life need to be considered pertaining to gender due to sexual segregation in Islam are as below:[488]

[488] Abdulaziz Abdulhussein Sachedina, *Islamic Biomedical Ethics Principles and Application*, (Oxford; New York: Oxford University Press, 2009), p. 195.

a. Individual duties – this includes the religious obligations to be carried out personally for God and other required actions, either privately or openly, such as performance of daily prayers and pilgrimage.
b. Relational ethics – this includes responsibilities towards others such as family and society in performing the duties guided by Islamic jurisprudence. Examples include matters related to guardianship, providing sustenance and the custody of children.
c. Rights concerning inheritance – there are specific legal guidelines on inheritance as mentioned in the Qurʾān which directly involve types of relationship and gender.
d. Specific ordinances that depend upon one's gender in terms of the penal code on retributive and restorative justice.

The medical perspective aims 'to improve physiological health and long term outcome as well as development of male or female sexual anatomy'.[489] To add another spectrum, treatment is vital to ensure patients' quality of life in term of psychological and psychosocial factors.[490] Treatment for gender issues seems to be the turning point for the new ascertained identity for patients to have a healthy life and appropriate gender behavioural roles as an individual, participant in a community and as a responsible religious adherent.

However, treatments for patients with DSD are not straightforward. To date, medical practitioners are still looking for a holistic guideline in managing the treatment of affected individuals. The large spectrum of rare disorders and the variable degree of the condition make it difficult to come up with proper protocol or guideline. Some treatments appear to be less complicated in terms of ethical issues for late-identified patients with DSD. The scenario is different for infants and children. Due to the social pressure, parents may ask for early medical intervention to avoid any delicate issue in the future. However, this poses an ethical dilemma that need to be addressed properly from the Islamic perspective.

[489] Jacqueline Hewitt and Margaret Zacharin, 'Hormone Replacement in Disorders of Sex Development: Current Thinking', *Best Practice & Research Clinical Endocrinology & Metabolism*, (2015), 1 – 11, p. 1.

[490] A. Nordernström, 'Psychosocial Factors in Disorders of Sex Development in a Long-Term Perspective: What Clinical Opportunities are there to Intervene?', *Hormone and Metabolic Research*, 47 (2015), 351 356, p. 351.

5.3. Surgical and Hormonal Treatments

Historically, treatment of hermaphrodites is closely related to surgical intervention. As early as in the 5th century, Ibn Sīnā opines that most of *khunthā* "are treated by removing the feebler organ and managing the injury."[491] Surgery has been performed in many cases to align the external genitalia with the assigned gender.[492] In the medical setting, surgery is required for three reasons:

a. to avoid potential health risks related to altered anatomy and function of urogenital tract;
b. to meet parents' expectations; and
c. to help affected individuals to achieve future satisfactory of sexual function.[493]

The atypical genitalia can affect "not only physical appearance and body image, but also the functions of the urinary tract, kidneys, gonads, and psychological and psychosexual development."[494]

Surgery in this context varies, depending on its risks for the long-term outcomes. It includes gonadectomy (removal of an ovary or a testis), external genitalia reconstructive surgery and surgery on the internal reproductive anatomy, even to the extent of organ transplantation (for instance, patients with Mayer-Rokitansky-Küster-Hauser syndrome (MRKH), who would need a uterus transplantation). The most debated intervention in managing patients with DSD is genitalia reconstructive surgery, also known as Sex Assignment Surgery (SAS) and gonadectomy. These interventions trigger the concern about informed consent, the appropriate timing of surgery, the best technique to use and the psychological consequences of having surgery or not having surgery due to its permanent and irreversible effects.[495] It is unfair to address these issues from Islam perspectives without firstly understand the actual

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[491] Al-Ḥusayn ibn ʿAli ibn Sīnā, *Al-Qānūn fī Al-Ṭibb*, ed. by Muḥammad Amīn al-Ḍannāwī, vol. 2 (Beirut: Dār al-Kutub al-ʿIlmiyyah, 1999), p. 746.

[492] A. Nordernström, p. 351.

[493] Pierre Mouriquand and others, 'An ESPU/SPU Standpoint on the Surgical Management of DSD', *Journal of Pediatric Urology*, 10 (2014), 8 – 10, p. 9.

[494] Pierre Mouriquand and others, p. 9.

[495] M. DiSandro, D. P. Merke and Richard C. Rink, 'Review of Current Surgical Techniques and Medical Management Considerations in the Treatment of Pediatric Patients with Disorders of Sex Development', *Hormone and Metabolic Research*, 47 (2015), 321 – 328, p. 325.

context of the treatment. Therefore, the following subtopic will briefly explain both surgical and hormonal treatments.

5.3.1. Surgical Treatments

Surgical interventions could be for urgent or elective surgeries.[496] The former refers to surgeries performed in order to avoid life-threatening circumstance or permanent disability such as the creation of unobstructed outlets for urine and stools. While the latter is the most typical type of surgical intervention for patients with DSD because 'assigning a sex of rearing to a child never requires surgery' – perhaps on SAS.[497] In most cases, SAS aims at good cosmetic appearance and functionality with potential for sexual intercourse.[498]

Current surgical techniques of feminizing genitoplasty for patients who are assigned as female include clitoroplasty, vaginoplasty and labioplasty. Clitoroplasty refers to surgical reduction of the clitoris by excising the middle portion of the phallus shaft and the shorter phallus is sewn back together. DiSandro et al. maintain that the current technique must involve the preservation of avoidance of injury.[499] However, little data can be found to support the positive physiological impact on sexual performance and gender comfortable identities.[500]

Vaginoplasty is the most complex portion of this surgery. This refers to the reconstruction of the vagina with several techniques such as 'cut-back', 'flap', 'pull-through' and 'complete vaginal replacement'.[501] Its effectiveness is difficult to assess, especially when conducted on infants and children, because it can only be completely assessed years later in adult age. Some cases require revisional surgery due to vaginal stenosis (narrowing vaginal openings), poor overall outcome or poor cosmetic

[496] Melissa Gardner and David E. Sandberg, 'Navigating Surgical Decision Making in Disorders of Sex Development (DSD)', *Frontiers in Paediatrics*, 6 (2018), 1 – 9, p. 2.

[497] InterACT, Advocates for Intersex Youth, *Medically Unnecessary Surgeries on Intersex Children in the US*, (United States of America: Human Rights Watch, 2017), p. 10.

[498] Lee et al. cited in Melissa Gardner and David E. Sandberg, p. 2.

[499] M. DiSandro, D. P. Merke and Richard C. Rink, p. 324.

[500] Nancy Ehrenreich and Mark Barr, 'Intersex Surgery, Female Genital Cutting, and the Selective Condemnation of Cultural Practices', *Harvard Civil Rights - Civil Liberties Law Review*, 20 (2005), 71 – 141, p. 111.

[501] M. DiSandro, D. P. Merke and Richard C. Rink, p. 324.

results.[502] Labioplasty is a cosmetic operation to develop the labia minora and clitoral hood that are created from the available clitoral skin.[503]

There are hundreds of surgical procedures for male reconstructive surgery, from straightforward procedures to complex operations.[504] For the more severe form of atypical genitalia, the rate of revisional surgery is high, and patients often require the second and third operations; a quarter of cases require an unplanned operation because of an emergency complication arises. Two types of surgery which have high success rate are chordee without hypospadias, to strengthen the penile gland; and distal hypospadias, to relocate the urethral opening situated near the tip of the gland.[505] The latter is not considered as a DSD by some doctors, because it does not lead to any functional impairment and is sometimes left untreated.

Proximal hypospadias is a complicated operation because the urethral opening is located on the underside of the penis. It has higher rates of complications and they often require reoperation.[506] Currently, a 2-stage operation is favourable due to its effectiveness. In the more severe undervirilised forms of patients assigned as male, the external genitalia appear to be female. The scrotum appears like labia and the urethral opening is located in the perineum just like in a typical female. In this case, penoscrotal transposition and bifid scrotum are conducted in numerous stages for scrotal reconstruction also for hypospadias and chordee correction. Even when these surgeries are successfully conducted, the patients may require multiple operations and experience secondary complications.[507]

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[502] Nancy Ehrenreich and Mark Barr, p. 107.

[503] M. DiSandro, D. P. Merke and Richard C. Rink, p. 324.

[504] M. DiSandro, D. P. Merke and Richard C. Rink, p. 325.

[505] M. DiSandro, D. P. Merke and Richard C. Rink, p. 325. Chordee refers to abnormal curvature or angulation of the penis. *Concise Medical Dictionary*, 8th edn (Oxford: Oxford University Press, 2010). [Online] Available at <https://www-oxfordreference-com.ezproxy.uwtsd.ac.uk/view/10.1093/acref/9780199557141.001.0001/acref-9780199557141> [accessed 15 November 2016].

[506] M. DiSandro, D. P. Merke and Richard C. Rink, p. 326.

[507] M. DiSandro, D. P. Merke and Richard C. Rink, p. 327.

5.3.2. Hormonal Treatments

DSD is closely associated with poor gonadal development and hormonal imbalances. 'Avoidance of some genital and gonadal surgery has led to significant changes in hormone treatment.'[508] It indicates that surgery is not the only solution to obliterate gender ambiguity. In certain conditions, hormonal treatment might provide alternative to surgical intervention. Male patients with DSD may require the use of oral testosterone or topical formulation to address issues of micropenis and acquire sufficient penile-length growth. Testosterone is also used for pubertal induction in order to develop male sexual secondary characteristics, bone mineral accrual and psychological development. Dihydrotestosterone (DHT) hormone is used to address the issue of undervirilisation in males and gonadotropin is administered to address the issue of fertility in hypogonadotrophic hypogonadism.[509]

Female patients with DSD and an absence of oestrogen that is secondary to gonadal dysgenesis require oestrogen hormone replacement for pubertal induction. Progesterone is added at puberty and it is necessary for patients who retain a uterus due to the risk of endometrial cancer – a cancer that begins in the layer of cells that form the lining of the uterus. However, oestrogen is not suggested for Turner syndrome due to cardiac anomaly risk and hypertension.

Undesired virilisation can occur among female patients with functional, androgen-producing gonads.[510] Typically, gonads-removal surgery, i.e. a gonadectomy is conducted to remove undesired testicular tissue and androgen production as well as to avoid germ cell cancer risk. As the surgery is irreversible and requires detailed discussion; a gonadotropin releasing hormone can be given instead, to suppress gonadotropin and androgen production. This alternative allows ample time for

[508] Jacqueline Hewitt and Margaret Zacharin, p. 9.

[509] Hypogonadotrophic hypogonadism (HH) is a clinical syndrome that results from gonadal failure and can cause issue of fertility. Read more in Renato Fraietta, Daniel Suslik Zylberstejn and Sandro C. Esteves, "Hypogonadotropic Hypogonadism Revisited", *Clinics (Sao Paolo)*, 2013(68)Supple 1: 81-88.

[510] Androgen is a group of steroid hormones that stimulate the development of male sex. *Concise Medical Dictionary*, 8th edn (Oxford: Oxford University Press, 2010). [Online] Available at <https://www-oxfordreference-com.ezproxy.uwtsd.ac.uk/view/10.1093/acref/9780199557141.001.0001/acref-9780199557141> [accessed 15 November 2016].

multidisciplinary team consensus, counselling for young patients and their informed consent.

Patients with Complete Androgen Insensitivity Syndrome (CAIS) are normally identified as having female external genitalia, woman's sexual secondary characteristics; yet also with the presence of testicular tissue. Gonadectomy is conducted to negate testicular germ cell cancer risk. However, studies have shown that the risk of cancer rises after puberty. It is thus recommended to postpone the surgery until after puberty. These CAIS patients are also at risk of osteoporosis due to the absence of testosterone's effects on bones. Hence, oestrogen hormone replacement is suggested for them.

Female CAH patients typically suffer clitoromegaly (an abnormal development of the clitoris due to excessive exposure to androgens) and fusion of labiascrotal folds that present as male genitalia. Previously, surgical reconstruction was proposed in infancy. However, there are concerns about long-term complications such as re-operation, reduced sexual sensation and function. Recently, the Endocrine Society published updated Clinical Practice Guideline for those with CAH due to 21-hydroxylase deficiency.[511] Hormonal treatment is recommended for all patients, including newborns and adults, according to its criteria.[512] There is a recommendation to use hormonal treatment as early as the prenatal period to suppress androgen, which stimulates the development of male genitalia. Antenatal treatment using dexamethasone is introduced for pregnancies that are identified as at high risk of producing babies with CAH. Nonetheless, prenatal hormonal treatment is still regarded as an experimental approach, and there are no specific guidelines provided by endocrinologists.

This subtopic 5.3 is presented to describe several types of surgical and hormonal treatment for patients with DSD. This does not represent all available treatments to date, but is sufficient to show there are several degrees of surgeries and various conditions that require surgical and hormonal treatments. Sometimes, hormonal

[511] Phyllis W. Speiser and others, 'Conginetal Adrenal Hyperplasia due to Steroid 21 Hydroxylase Deficiency: An Endocrine Society (Clinical Proactive Guideline)', *Journal of Endocrinology Metabolism*, 103 (2018), 4043-4088.

[512] Phyllis W. Speiser and others, p. 4043.

treatments alone are sufficient and are alternatives to surgery. This understanding is vital for the evaluation from the Islamic perspectives as will be described further in weighing the most important surgical intervention that should be prioritised.

5.4. Discursive Contestation of the Existing Treatment for Patients with Disorders of Sex Development (DSD)

Early surgery is anticipated to accommodate the social expectations of the binary concept of gender and has been broadly accepted. Thus, surgery has traditionally been considered as in the infant's best interest so he/she will grow up like any other child, i.e. without psychological and emotional pressure because of their condition. Parents chose quick action to 'normalize' their child's appearance as they viewed genital surgery as necessary to good psychosocial and psychosexual adaptation.[513] It is imbued in the optimal gender policy that healthy psychosexual development is largely dependent on the clear manifestation of genitalia.[514] As mentioned in the previous chapter, John Money proposed early surgery for infants at 18 months to 'normalize' the genitalia. This protocol is still being referred to by the medical practitioners of today, despite criticisms and recommendations for postponing surgery.

Rahmah Rasat argues that postponement is not applicable for all cases of DSD. It depends on the diagnosis.[515] The same argument is observed when Nasir A. M. Jurayyan recommends that early surgical reconstruction be conducted in three conditions.[516] First is for chromosome 46,XX (female) children with normal ovaries and internal female organs (uterus, fallopian tubes and upper vagina), but with some degree of virilisation of the external genitalia. A high fertility rate is assured in this case and therefore, the corrective surgery is recommended before 2 years of age. Second is for chromosome 46,XY (male) children with CAIS or testicular feminization. Due to androgen insensitivity and a lack of testosterone response, external genitalia will look similar to those of a female, as mentioned in subtopic 4.5.2, Chapter 4 on A.D. Fisher

[513] Melissa Gardner and David E. Sandberg, p. 2

[514] John Money and A. A. Ehrhardt, *Man and Woman, Boy and Girl: Gender Identity from Conception to Maturity* (Baltimore: The John Hopkins University Press, 1973), p. 310.

[515] Rahmah Rasat, *Telephone Conversation with Taqwa Zabidi* (1 August 2016).

[516] Nasir A. M. Al-Jurayyan, 'Disorders of Sex Development: Diagnostic Approaches and Management Options - an Islamic Perspective', *Malaysian Journal Medical Science*, 18 (Jul - Sep 2011), 4-12. Jurayyan is a Professor at Department of Paediatrics, College of Medicine, and King Saud University, Saudi Arabia.

and others' recommendation of gender assignment. It is advised to undergo a gonadectomy at the time of diagnosis and before puberty to avoid the adverse effects of testosterone and minimise the risk of the development of gonadoblastoma. The third circumstance is among children who are diagnosed with 5-α reductase deficiency, because further virilisation always occurs at puberty along with development of male characteristics. Therefore, the male gender is appropriate for them and surgical reconstruction should be performed as early as 18 months.

There is no doubt concerning the importance of conducting urgent surgery in the case of medical emergencies. However, great concern has been raised concerning the harmful effects of early elective surgeries.[517] Terms such as 'medically unnecessary surgery', 'cosmetic surgery' and 'genital normalizing surgery' are used to show strong objection to early elective surgery on infants and children.[518] In 2013, Juan E. Méndez, a Special Rapporteur to the United Nations, submitted a report on torture and other cruel, inhuman or degrading treatment or punishment. 'Torture' is exemplified with four elements provided in the Article 1 of the Convention Against Torture as; an act inflicting severe pain or suffering, whether physical or mental; the element of intent to harm or hurt; the specific purpose of the action; and the involvement of a State official, at least by acquiescence.[519] He reported torture on children with DSD, whom he grouped with lesbian, gay, bisexual, transgender, and intersex person under the subtopic of Marginalized Groups as follows:

> "Children who are born with atypical sex characteristics are often subject to irreversible sex assignment, involuntary sterilization, involuntary genital normalizing surgery, performed without their informed consent, or that of their parents, "in an attempt to fit their sex", leaving them with permanent, irreversible infertility and causing severe mental suffering."[520]

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[517] Anne Tamar-Mattis, *Reports to the UN Committee Against Torture: Medical Treatment for People with Intersex Condition*, (United States: Office of the High Commissioner of Human Rights, 2014), p. 1 [Online] Available at <https://tbinternet.ohchr.org/Treaties/CAT/Shared%20Documents/USA/INT_CAT_CSS_USA_18525_E.pdf> [accessed 9 September 2019]; A. A. Kon, 'Ethical Issues in Decision-Making for Infants with Disorders of Sex Development', *Hormone and Metabolic Research,* 47 (2015), 340-343, p. 340.

[518] Juan E. Méndez, *Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment Or Punishment,* A/HRC/22/53 (United Nations General Assembly, 2013), p. 1; InterACT, Advocates for Intersex Youth, p. 8; Melissa Gardner and David E. Sandberg, p. 1.

[519] Juan E. Mèndez, p. 18.

[520] Juan E. Mèndez, pp. 18 -19.

In 2014, Anne Tamar-Mattis, the founder of InterACT (an organisation based in the United States) forwarded an individual report to the United Nations against torture in the medical treatment for patients with DSD.[521] Later, InterACT collaborated with Human Rights Watch in conducting research on the consequences of early surgery on DSD children. The research was based on in-depth interviews with 30 intersex adults, two intersex children, 17 parents of intersex children, six parents of CAH children, three individuals with CAH and 21 healthcare practitioners from various medical backgrounds in the United States.[522] Although the move to prevent early surgery began in the United States, the issue has spurred worldwide concerns and ethical dilemmas.

5.4.1. Physical and Physiological Harm

Despite the often-satisfactory outcomes of early elective surgeries, there have been a number of cases reported on dissatisfaction with the results.[523] This may be due to three factors, i.e. later sexual development against the assigned sex, complication and dissatisfaction with the results. The standard of care for infants and children has prioritized feminising over masculinization because it is technically easier to construct a vaginal canal than a phallus. In a longitudinal study, it was reported that 17 out of 18 patients with 5-α reductase deficiency who were assigned as female later changed gender identity to male.[524] This would lead to gender dysphoria, a condition which will be discussed in a later subtopic. There have been reports that surgery has led to genital dysfunction, scarring, loss of sexual feeling, loss of fertility, chronic pain, and the wrong gender assignment with irreversible excision of genital and gonadal tissue.

[521] Anne Tamar-Mattis, p. 1.

[522] InterACT, Advocates for Intersex Youth, pp. 53-113.

[523] Satisfactory surgery on children was mentioned in I. A. Hughes and others, 'Consensus Statement on Management of Intersex Disorders', *Journal of Pediatric Urology,* 2 (2006), p. 154. For more details, please refer to Lee PA, Witchel SF, 'Genital Surgery among Females with Congenital Adrenal Hyperplasia: Changes over the Past Five Decades', *Journal Pediatric Endocrinology Metabolism* 15 (2002), 1473-1477.

[524] This is parallel with what Jurayyan mentioned on the condition of patients who were diagnosed with 5-α reductase deficiency as well as the recommendation made by A.D. Fisher and others in subtopic 4.5.2, Chapter 4.

In certain complicated cases, surgical diagnostics are required. The procedures include exploratory laparotomy, laparoscopy, gonadal biopsy and others.[525] Rahmah Rasat mentioned that,

> "The first two months for baby is the best time to conduct the diagnosis because the hormone is so active. And, that period is within the first six months that we call it as 'mini-puberty' when the baby is looked like at the puberty stage. After six months, everything goes flat and low… Sometimes, we need to use x-ray and ultrasound to observe the streak… Sometimes, we need to subject the patients to laparoscopy, i.e. inserting a small tube into the body. But that will be the last choice."[526]

While some surgeries need to be repeated multiple times such as vaginoplasty, which has a high rate of failure especially when it is conducted at infancy, it causes substantial pain during childhood.[527] Vaginoplasty as well as clitoroplasty techniques lead to poor sexual enjoyment due to scarring of the clitoral skin.[528]

5.4.2. Psychological Harm

Physical and physiological harms may affect the emotions and psychology of children. The optimal gender policy, which underscores the future well-being of the children, is initially appreciated to minimize any such issues, as the surgery is conducted prior to children's psychological maturity. However, efficacy of the surgery takes years of monitoring and follow-ups. The procedures involved in frequent invasion of another's private parts (which are privileged as private in Islam and many) can cause mental and emotional harms.[529]

5.4.3. Gender Dysphoria

Some cases of DSD would lead to gender dysphoria at a later age, especially for female Congenital Adrenal Hyperplasia (CAH) patients and patients with Partial

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[525] Nabil M. Dessouky, 'Gender Assignment for Children with Intersex Problems: An Egyptian Perspective', *Egyptian Journal of Surgery,* 20 (April 2001), 419 – 515, p. 500.

[526] Rahmah Rasat, *Telephone Conversation with Taqwa Zabidi* (1 August 2016).

[527] Nancy Ehrenreich and Mark Barr, p. 107.

[528] Nancy Ehrenreich and Mark Barr, p. 111.

[529] Sayed S. Haneef and Mahmood Zuhdi Abdul Majid, 'Medical Management of Infant Intersex: The Juridico-Ethical Dilemma of Contemporary Islamic Legal Response', *Zygon: Journal of Religion & Science*, 50 (December 2015), 809-829, p. 825.

Androgen Insensitive Syndrome (PAIS). These two groups can sometimes become aggravated insisting that they should be allowed to determine their own gender, instead of early determination in infancy. We recap the condition of CAH for better understanding of how it could lead to gender dysphoria. Jalaluddin explained that the most common CAH cases are caused by 21-hydroxylase deficiency.[530] The patients face a shortage of cortisol and aldosterone hormone and are highly exposed with testosterone secreted by the adrenal glands since in the womb due to several factors during pregnancy. Excessive exposure to testosterone at this stage, although present briefly, is assumed to persist across the lifespan and has been indicated to have influences on brain and sexual behaviour producing more male characteristics. If a child is chromosomally identified as a boy, 46,XY, there would not arise the issue of sex assignment. However, cases are different for 46,XX children with CAH who, in most cases, retain internal female organs with virilised genitalia and yet show male behaviour at adolescence.[531]

5.4.4. Postponement of the Surgeries

In a conference on DSD attended by the researcher at Ghent, Belgium in 2015, there a non-governmental organisation assembled in front of the conference venue during the 3-day programme. The group proposed stopping any treatment related to genital cutting. Perhaps the adverse effects inflicted upon affected persons triggered the need for the protest in order to deliver the message to surgeons and other doctors in the conference to take the matter of gender assignment seriously.

The harmful effects of misassignment at birth have caused a public outcry and significant recommendations have been forwarded for delaying such surgery. Subsequently, Anand Grover, a Special Rapporteur on the Right to Health for United Nations General Assembly, provided a report arguing for postponement of surgery until the children can participate in the decision-making process. He views the surgery

[530] Yazid Jalaludin, *Telephone Conversation with Taqwa Zabidi*, (17 September 2016).

[531] Yazid Jalaludin, 17 September 2016. Please refer the scenario of the abnormal development of the internal and external genitalia in the Appendix D (Transcription of an Interview).

as ‘a painful and high-risk procedure with no proven medical benefits’.[532] He states that,

> “Health-care providers should strive to postpone non-emergency invasive and irreversible interventions until the child is sufficiently mature to provide informed consent. Safeguards should be in place to protect children from parents withholding consent for a necessary emergency procedure.”[533]

This statement has been supported by research based on the need for ‘informed consent’ in order to minimize the risk of elective surgeries.[534] Although it does not comment exactly on the timing of the surgeries, it indicates that most surgical interventions should be postponed, especially for the minor patients, until they have the ability to participate in the decision-making process and exercise the principle of patient autonomy.

5.5. Medical Intervention in Islamic Perspectives

A study was conducted by the researcher elsewhere in analysing fatwas around the globe on matters pertaining to gender ambiguity.[535] Permissibility of sex assignment surgery was identified as the most discussed by juristic councils within the continuum of resolving gender ambiguity issues, although the debate is far beyond the issue of permissibility or prohibition in the medical setting. Among others, they are the Islamic Fiqh Academy Muslim World League, Council of Senior Scholars Saudi Arabia, Islamic Council for Fatwa Palestine, Fatwa Committee of the National Council of Islamic Religious Affairs, Malaysia, Council of Indonesian Scholars and Islamic Fiqh Academy

[532] Anand Grover, *Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard to the Physical and Mental Health,* A/64/272 (United Nations General Assembly, 2014), p. 15 [Online] Available at <https://digitallibrary.un.org/record/663926#record-files-collapse-header> [accessed 9 September 2019].

[533] Anand Grover, pp. 14-15.

[534] M. DiSandro, D. P. Merke and Richard C. Rink, p. 321; A. A. Kon, p. 340; Nancy Ehrenreich and Mark Barr, p. 71; Melissa Gardner and David E. Sandberg, p. 1; Peter A. Lee and others, 'Global Disorders of Sex Development Updates since 2006: Perceptions, Approach and Care', *Hormone Research in Paediatric,* (2016), 1-23.

[535] Taqwa Zabidi, ‘Analytical Review of Contemporary Fatwas in Resolving Biomedical Issues over Gender Ambiguity’, *Journal of Religion and Health,* 1 (2018), https://doi.org/10.1007/s10943-018-0616-0, 1-15. The research is conducted over 13 juristic councils who practice consultative and collective approach. The establishment of those councils are either at national, regional or international levels and the fatwas were observed via online and offline inputs. These councils are accessible in either English, Arabic or Malay.

India.[536] All of them unanimously agree on the permissibility of sex assignment surgery for *khunthā*.[537]

The Islamic Fiqh Academy Muslim World League, an international jurist council based in Mecca, differentiates between the terms of sex change and sex assignment (*taḥdīd al-jins*).[538] Sex change simply refers to the condition of those people with gender dysphoria without any biological aberrant, while sex assignment refers to people with DSD. Similar connotations were also used by the Council of Indonesian Scholars (*Majelis Ulama Indonesia*) when it addressed sex-change operation (*operasi ganti kelamin*) for transsexuals and sex recuperation surgery or corrective surgery (*operasi penyempurnaan kelamin*) for *khunthā* in its decrees.[539]

It is very clear that any medical actions taken for the purposes of treatment are permissible unless they are proven to be against Islamic teachings as indicated in the following:

> "I (Usāmah ibn Sharīk- a Companion) was with the Prophet when the Bedouins came to him and said, 'O Messenger of Allah, should we seek medicine?' He said, 'Yes, O slaves of Allah, seek medicine, for Allah has not created a disease

[536] Islamic Fiqh Academy Muslim World League, *Majallah al-Majmaʿ al-Fiqh al-Islāmiy (Journal of Islamic Fiqh Academy)* vol. 8 (Mecca: al-Majmaʿ al-Fiqh al-Islāmiy, 2004), p. 341; Ṣāliḥ Fawzān Al-Fawzān, *Al-Fatāwā Al-Mutaʿalliqah Bi Al-Ṭibb Wa Aḥkām Al-Marḍā (Verdicts in Relation to Medicine and Rulings on Patients)* (Riyadh: Riʾāsah Idārah al-Buḥuth al-ʿIlmiyyah wa al-Iftāʾ, 1424H), pp. 305-306; The Islamic Council for Fatwa Bayt al-Maqdis, *Taṣḥīḥ Jins Al-Khunthā Bi Wāsiṭah Al-ʿAmaliyyāt Al-Jaraḥiah* (Corrective Hermaphrodite's Gender Via Surgery), (Palestine: 2012) [Online] Available at <*http://www.fatawah.net/Fatawah/658.aspx*> [accessed on 12 June 2016]; Department of Islamic Development Malaysia, *Decision of the Fatwa Committee of the National Council for Islamic Religious Affairs Malaysia,* pp. 74 - 75; Majelis Ulama Indonesia, *Himpunan Fatwa MUI (Collections of MUI Fatwa)*, ed. by Hijrah Saputra, Andriansyah and Andhika Prasetya K. S.Sos (Indonesia: Erlangga, 2011), p. 571; Islamic Fiqh Academy India, *Qarārāt wa Tawṣiyyat Majmaʿ al-Fiqh al-Islāmiy bi al-Hind (Decisions and Recommendations of Islamic Fiqh Academy India)* ed. by Niʿmatullah Al-Aʿẓamī, Muḥammad Burhān Al-Dīn Al-Sunbahilī, Badr Al-Ḥasan Al-Qāsimī, Khālid Sayfullah Al-Raḥmānī, ʿAtīq Aḥmad Al-Bistawī, ʿUbaydullah Al-Asʿadī, 13th edn. (India: Islamic Fiqh Academy, 2012).

Council of Senior Scholars was formally established on 29 August 1972 as the highest religious body and advisory panel to the King of Saudi Arabia on religious matters. It is head by the Grand Mufti of the kingdom. The Islamic Council for Fatwa Bayt al-Maqdis is a juristic council for Palestine who issues fatwa locally on various religious matters.

[537] The decisions were made by Islamic Fiqh Academy Muslim World League in its 11th conference in 1989; Council of Senior Scholars Saudi Arabia in fatwa no. 176 on its 39th Conference 1992; Islamic Council for Palestine in fatwa no. 658/2012; Islamic Fiqh Academy India in fatwa no. 78 (18/3); Fatwa Committee of the National Council of Islamic Affairs, Malaysia in the 4th Conference 1982, the 25th Conference 1989 and the 76th Conference 2006; and Religious Council of Indonesia in fatwa no. 3, 2010.

[538] Islamic Fiqh Academy Muslim World League, p. 306

[539] Majelis Ulama Indonesia, p. 571. More elaboration on Majelis Ulama Indonesia can be found in Chapter 7.

> except that He has also created its cure, except for one illness.' They said, 'And what is that?' He said, 'Old age'.[540]

Any alteration of Allah's creation including sex change surgery conducted merely to accommodate one's desire, without any dire need, is prohibited as it falls under the category 'vain alteration'. The prohibition is rendered upon a verse in the Qurʾān that associates such actions with Satan's wickedness:

> "I will mislead them, and I will create in them false desires; I will order them to slit the ears of cattle, and to deface the (fair) nature created by Allah." Whoever, forsaking Allah, takes Satan for a friend, hath of a surety suffered a loss that is manifest."[541]

Allah repeatedly reminds humans in the Qurʾān not to follow Satan's action, for they will mislead people to go astray from the teachings of Islam.[542]

However, reconstructive surgery is permissible due to the need of eliminating harm and bewilderment. 'A permanent legal remedy to rectify gender identification was deemed not only worthy but essential.'[543] Hence, the clear understanding of such conditions is fundamental to its management.

Sex-assignment surgery certainly comes with a bundle of risks including mutilation, disfigurement and/or rejection of foreign implants.[544] Even al-Nawāwī, a Shāfiʿī scholar in 7th century, states that cautery should be the last resort after all other clinical management has been deemed inappropriate.[545] It is based on a Ḥadīth narrated by Jābir that when the Prophet sent a doctor to Ubay ibn Kaʿab, and that the doctor cut

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[540] Muḥammad Ibn Yazīd Ibn Mājah, *Sunan Ibn Mājah*, ed. by Farīq Bayt al-Afkār al-Dawliyyah, edn. 2 (Saudi Arabia: Bayt al-Afkār al-Dawliyyah, 1999), p. 372. Ḥadīth No. 3436, Book *al-Ṭibb* (Medicine), *Bāb Ma Anzal Allah Dāʾ Illa Anzal Lah Shifāʾ* (Chapter Allah will not send down disease except He send with it remedy). Al-Būṣirī notes this is an authentic Ḥadīth.

[541] Translation of the Qurʾān in ʿAbdullah Yūsuf ʿAlī, *The Holy Qur´an Text, Translation and Commentary*, New Revised edn (Brentwood: Amana Corporation, 1989), *Sūrah al-Nisāʾ* (The Women), 5: 119.

[542] Allah repeats three times in *Sūrah al-Baqarah* (The Heifer), 2: 168 and 208, and *Sūrah al-Anʿām* (The Cattle), 6: 142 reminding the believers (translated as), "and follow not the footsteps of the Satan; for he is to you an avowed enemy." Again, it is mentioned in *Sūrah al-Nūr* (The Light), 24: 21, "O ye who believe! Follow not Satan's footsteps: if any follow the footsteps of Satan, he will (but) command what is shameful and wrong, …" Satan commands people on "what is evil and shameful, and that ye should say of God that which ye have no knowledge." Translation of *Sūrah al-Baqarah*, (The Heifer), 2: 169.

[543] Abdulaziz Abdulhussein Sachedina, *Islamic Biomedical Ethics Principles and Application*, (Oxford; New York: Oxford University Press, 2009), p. 194.

[544] Abdulaziz Abdulhussein Sachedina, p. 194.

[545] Muḥy Al-Dīn Al-Nawāwī, *Al-Minhāj Sharḥ Ṣaḥīḥ Muslim ibn al-Ḥajjāj (Way of Explication of Authentic Ḥadīth of Muslim)* edn. 2, vol. 14 (Beirut: Dār Iḥyāʾ al-Turāth al-ʿIlmī 1392H), p. 193.

his artery and cauterized the wound in order to stop the bleeding.[546] The technique of cauterization is still currently being used by surgeons to seal blood vessels during surgery to prevent blood loss and keep the site clean.[547] However, the Prophet himself disliked cautery and stated that an operation requiring it should be postponed after all other interventions have been taken into consideration.

Thus, hormonal treatment and other appropriate clinical management should first be taken into consideration. Clearer guidelines can be found in the Bayt al-Maqdis' fatwa, which states that there should be confirmation of:

a. health risk condition;
b. surgery as the last resort of the treatment;
c. high probability of benefits by assigning the gender;
d. acceptance of the surgical treatment by the patient; and
e. availability of expert surgeons and their assistants.[548]

This fatwa addresses Haneef and Abdul Majid's qualm about whether 'is it justified in Islamic law to resort to assignment surgery in the first place?'[549] The guidelines in this decree are certainly accommodating to the medical practitioners.[550]

A hormonal or surgical approach to *khunthā wāḍiḥ* (discernible) is permissible whenever the dominant characteristics either of maleness or femaleness are clear as discussed in the Chapter 4.[551] The treatment should be conducted with the consent of the legally major and rational patient or the approval of the guardian for a minor patient, as stipulated in the decree of the Council of Senior Scholars Saudi Arabia.[552]

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[546] Abu al-Ḥusayn Muslim Al-Ḥajjāj, *Ṣaḥīḥ Muslim (Authentic of Muslim)*, ed. by Muḥammad Fuad ʿAbd Al-Bāqī, 2nd edn, vol. 4, (Beirut: Dār al-Kutub al-ʿIlmiyyah, 1991), p. 1730. Ḥadīth no.: 2207, Book *al-Salām* (Peace). An authentic Ḥadīth.

[547] Cautery or modern technique of electrocautery is an ancient method that is still important to be applied in current surgical intervention. Read examples of its use in *Essential Practice of Surgery: Basic Science and Clinical Evidence*, ed. by Jefrey A. Norton (New York: Springer-Verlag, 2002).

[548] The Islamic Council for Fatwa Bayt al-Maqdis, *Taṣḥīḥ Jins Al-Khunthā Bi Wāsiṭah Al-ʿAmaliyyāt Al-Jaraḥiah*, para 16-21 of 22.

[549] Sayed S. Haneef and Mahmood Zuhdi Abdul Majid, p. 825.

[550] Taqwa Zabidi, 'Analytical Review', p. 11.

[551] Islamic Fiqh Academy Muslim World League, p. 341; Ṣāliḥ Fawzān Al-Fawzān, p. 306; United Arab Emirates, 'Min Aḥkām al-Khunthā (Among the Rulings of Hermaphrodite)' *General Authority of Islamic Affairs and Endowment*, 9 May 2016 [Online]. Available at <http://www.awqaf.gov.ae/Fatwa.aspx?SectionID=9&RefID=2571> [accessed: 10 May 2016]; The Islamic Council for Fatwa Bayt al-Maqdis, para 9 of 22; Department of Islamic Development Malaysia, pp. 74 – 75.

[552] Ṣāliḥ Fawzān Al-Fawzān, p. 181.

In contrast, surgical treatment is not allowed for *khunthā mushkil* whenever the signs of masculinity or femininity are vague to avoid any futile act, as determined by the juristic council of the General Presidency of Scholarly Research and Iftāʾ, Saudi Arabia. Performing unnecessary surgery contradicts to the reminder of the Prophet SAW, in his last sermon, "… Verily, your blood, your property and your honour are sacred to one another…"[553] Subsequently, *fiqh khunthā* is applied for them including prohibition of marriage due to indeterminate sex.[554]

On another hand, surgery is only permissible to be conducted by expert surgeons. Those who are unqualified and take risks, bare the liability. This is based on a Ḥadīth by the Prophet SAW, which states "He who undertakes (*taṭabbaba*) the treatment of others, without preparing himself and causes loss of life or damage is held liable."[555] Ibn Qayyim (d. 748 AH/1347AH) explains that the term '*taṭabbaba*' refers to a huge effort of act as a doctor, yet he/she has no reliable expertise for treating patients. It is a 'profess to be a physician… self-proclaim, allege, purport or fake.'[556] This Ḥadīth is a great reminder to the physicians to ensure their ability in conducting their tasks and obligations. Their credibility is proven through their qualifications including acquiring 'knowledge, balance, confidence, patience, forbearance, fear of wrongdoing, and similar professional characteristics, besides mastering the use of the tools of the profession.'[557]

The issue whether or not Muslim patients with sex ambiguity can receive proper treatment is now clearer. The more complex issue is whether surgical treatment for

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[553] Muḥammad ibn Ismāʿil al-Bukhārī, *Ṣaḥīḥ Al-Bukhārī*, ed. by Abū Ṣuhayb al-Karamī (Saudi Arabia: Bayt al-Afkār al-Dawliyyah, 1998), p. 38. Ḥadīth no. 67, *Kitāb al-ʿIlm* (Book of Knowledge), *Bāb Rubb Muballagh Auʿā Min Sāmiʿ* (Chapter Perhaps Informant Comprehends Better than Listener). Authentic Ḥadīth.

[554] General Presidency of Scholarly Research and Iftāʾ, *Fatāwā Al-Lujnah Al-Dāʾimah (Fatwa of General Presidency)*, ed. by Aḥmad ʿAbd Al-Razāq Al-Duwaish, vol. 25 (Riyadh: Riʾāsah Idārah al-Buḥūth al-ʿIlmiyyah wa al-Iftāʾ, n.d.), p. 49; United Arab Emirates. General Presidency of Scholarly Research and Iftāʾ (*al-Lajnah al-Dāʾimah li al-Buḥūth al-ʿIlmiyyah wa al-Iftāʾ*) also known as the Standing Committee of Scholarly Research and Iftāʾ was established in 29 August 1971 by the Saudi Arabia's royal decree to assist in preparing research papers for Council of Senior Scholars (King advisory council of religious matters) and to issue fatwa on individual issues.

[555] Abū Dāud, Abū Sulayman Ibn al-Ashʿath, *Sunan Abī Dāud*, ed. by ʿAbd al-Ḥamīd, Muḥammad Maḥy al-Dīn, vol. 4, (Beirut: Al-Maktabah Al-ʿAṣriyyah, n.d.). p. 195. *Bāb fī man taṭabbaba bi ghayr ʿilm faʾaʿnt* (Chapter Who Medically Treats a Person without Knowledge, He Held Liability). Al-Albānī notes this is a good (*ḥasan*) Ḥadīth.

[556] Shamsuddin Muḥammad ibn Abī Bakr ibn Qayyim al-Jawziyyah, *Al-Ṭibb Al-Nabawī (The Prophetic Medicine)*, ed. by ʿAbd al-Ghinā ʿAbd al-Khāliq, ʿAdil al-Azharī, Maḥmūd Farraj al-ʿUqdah (Beirut: Dār al-Fikr, n.d.), p. 110.

[557] Shamsuddin Muḥammad ibn Abī Bakr ibn Qayyim al-Jawziyyah, *Al-Ṭibb Al-Nabawī*, pp. 112-114.

minor patients may be conducted amidst its reported harmful effects? Secondly, are ultimate outcomes associated with the surgery depend on its timing? Whether 'performing genital surgery later (or not all) may result in better, poorer, or comparable physical, psychosocial and psychosexual outcomes.'[558]

5.6. *Maṣlaḥah* (Public Interest) as a Measuring Control

The researcher does not deny the importance of informed consent as will be thoroughly discussed in Chapter 6 on the decision making process. The treatment may be postponed to cater for the notion of patient autonomy. Yet, the patients then bare risks of the abnormal development throughout their upbringing. Haneef and Abdul Majid urge Islamic jurists and jurist-consults to go beyond the notion of *maṣlaḥah* in protecting life and family, to legitimise surgical treatment due to ethical issues.[559] Therefore, the researcher argues for the analysis of *maṣlaḥah* as a measuring control in response to the question of when the surgical intervention should occur. Understanding benefits and harms associated with the time of action is seen as the more critical area. It is absolutely necessary prior to/and in order to give informed consent. This measure will provide a wider scope for a framework across age and time of procedure.

Mohamed and Mohamed Noor propose the utilization of *maqāṣid al-sharīʿah* (the objectives of sharīʿah) as a mechanistic tool in resolving moral dilemmas in medical practice especially in handling issues of newborns with DSD.[560] The concept of *maqāṣid al-sharīʿah*, as explained in Chapter 2, is viewed by them as flexible, dynamic and a creative tool in handling various social policies.[561] This is manifested in the realisation of *maṣlaḥah* (benefit) to promote public interests and to prevent social evils.

[558] Melissa Gardner and David E. Sandberg, p. 3.

[559] Sayed S. Haneef and Mahmood Zuhdi Abdul Majid, p. 826.

[560] *Maqāṣid al-sharīʿah* is the concept that underlies the Islamic rulings since its inception. The term was never mentioned in the Divine texts. It was coined when the discipline of principles of Islamic jurisprudence evolved. Scholars such as al-Shāṭibī proposed the understanding of this concept. Later, it was expanded by other contemporary scholars such as Ibn ʿAshūr, ʿAllāl al-Fāsī, ʿAbdullah Bin Bayyah, al-Raysūnī and Jasser Auda.

[561] Mohd Salim Mohamed and Siti Nurani Mohd Noor, 'Islamic Bioethical Deliberation on the Issue of Newborns with Disorders of Sex Development', *Science and Engineering Ethics,* 20 (25 Mar 2014), 429-440, p. 439.

Supporting Mohamed and Mohamed Noor's argument, the researcher is inclined to use *maṣlaḥah* (benefit for promote public interest) itself as the mechanistic tool rather than *maqāṣid al-sharīʿah*. It is because *maqāṣid al-sharīʿah* refers to the general framework of sharīʿah in achieving the ultimate goals of Islamic law. *Maṣlaḥah*, on the other hand, is the element that needs to be observed in the fulfilment of the *maqāṣid al-sharīʿah*. Al-Ghazālī (d. 505 AH/1111 CE) defines *maṣlaḥah* as one of:

> "The benefits that are intended by the Lawgiver [God] for mankind in the preservation and protection of religion, life, mind, progeny and wealth. Whatever ensures the protection of these five elements is *maṣlaḥah* and whatever causes the missing of these five elements is harmful (*mafsadah*), and to remove it is a *maṣlaḥah*."[562]

Ibn ʿAshūr (d. 1973) a contemporary scholar, describes *maṣlaḥah* as a characteristic attributed to an action that result into goodness, which benefits public or individuals continuously or in most occasions.[563]

Al-Ghazālī divides *maṣlaḥah* into three categories: *maṣlaḥah muʿtabarah* (benefits that are acknowledged by the *sharīʿah*); *maṣlaḥah mulghāh* (benefits that are rejected by the *sharīʿah* such as usury; and *maṣlaḥah mursalah* (benefits that are neither acknowledged nor rejected by the *sharīʿah*).[564] Many current policies, guidelines and rules can be reviewed in terms of *maṣlaḥah mursalah* in which there is no direct Divine revelation on such matters. This later type is divided into three stages according to its strength, namely 'necessity' (*ḍarūriyyāt*), 'complimentary' (*ḥājiyyāt*) and 'embellishment' (*taḥsīniyyāt*).

'Necessity' is the highest level regarding benefits. It depicts things, upon which the lives of people depend and the neglect of which will cause complete disruption or collapse. It encompasses of the preservation of five elements, i.e. faith, life, mind, progeny and wealth. This level would decline to the level of 'complimentary' or 'embellishment' depending on the extent of their consequences. If it does not cause any disruption but would lead to hardship in its absence, it is categorised as

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[562] Muḥammad Muḥammad Al-Ghazālī, *Al-Mustaṣfā fī ʿIlm Al-Uṣūl (the Seeking of Purity in the Science of Jurisprudence's Principles)*, ed. by ʿAbd al-Salām ʿAbd al-Shāfī (Beirut: Dār al-Kutub al-ʿIlmiyyah, 2000), p. 147.

[563] Al-Ṭāhir Ibn ʿAshūr, *Maqāṣid al-Sharīʿah al-Islāmiyyah (Objectives of Islamic Jurisprudence),* ed. by Muḥammad al-Ṭāhir Al-Mīsāwī (Jordon: Dār al-Nafāʾis, 2001), p. 278.

[564] Muḥammad Muḥammad Al-Ghazālī, *Al-Mustaṣfā,* p. 146.

complimentary. At this stage, actions are really required to fulfil the interests.[565] The level of 'embellishment' is supplementary to the two levels of 'necessity' and 'complimentary' in order to enhance, ameliorate and make things easier in certain customs and transactions.[566]

Al-Būṭī (d. 2013), a renowned Syrian scholar, outlines five principles of *maṣlaḥah* as a guideline to identify and recognise it from the Islamic perspectives. The principles are enumerated as follows:

a. *Maṣlaḥah* is in accordance with the higher intent of the Lawgiver.
b. *Maṣlaḥah* is in line with the Qurʾān.
c. *Maṣlaḥah* is in line with the Ḥadīth.
d. *Maṣlaḥah* is in line with *qiyās*.
e. The most imperative *maṣlaḥah* (benefits) should be prioritized.[567]

He continues to explain the latter principle in which benefits may come in variable degrees on varying occasions. In the case of overlapping benefits, the most vital one is chosen based on three aspects in its order that are 'strength', 'prevalence' and 'implication'.

As al-Ghazālī notes on the element of 'strength' that the three levels are analysed according to their order. Protecting of the five elements of *maṣlaḥah* i.e. faith, life, mind, progeny and wealth in the descending order are essential at the level of 'necessity'.[568] Faith is given priority over life, mind, progeny and wealth. Wealth or property are the last to be considered when there are overlapping benefits that require primary concern.

In order to analyse whether such surgical intervention should be done soon after an early diagnosis or postponed to later age, the level of *maṣlaḥah* must be ensured, as shown in Table 7. The reason for gonadectomy and SAS are:

a. to protect life (*ḥifẓ al-nafs*) in seeking better functioning genitalia; and
b. to protect progeny (*ḥifẓ al-nasb*) in ensuring fertility of the patients.

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[565] Muḥammad Muḥammad Al-Ghazālī, *Al-Mustaṣfā*, p. 147.
[566] Muḥammad Muḥammad Al-Ghazālī, *Al-Mustaṣfā*, p. 147.
[567] Muḥammad Saʿīd Ramaḍān Al-Būṭī, *Ḍawābiṭ al-Maṣlaḥah fī al-Sharīʿah al-Islāmiyyah (Principles of Public Interests in Islamic Law)*, (Beirut: Muʾassasah al-Risālah, 1973), p. 115.
[568] Muḥammad Muḥammad Al-Ghazālī, *Al-Mustaṣfā*, p. 147.

If the surgery is required due to critical and/or life-threatening conditions that would bring imminent harm and risks to the patients, which is categorised as the urgent surgery, then it is necessary to be conducted immediately. Elective surgeries such as vaginoplasty, clitoroplasty and gonadectomy, as explained in subtopic 5.3 in this chapter, are vital and recognised in the 'complimentary' level. Looking at the complications of early surgery in this category, it should be postponed if it is believed the risks of surgical postponement are low. On the other hand, if the surgery is for cosmetic purposes, such as labioplasty or distal hypospadias, it does not require urgent intervention. Hence, postponement is appropriate.[569]

The basis of identifying the stages of *maṣlaḥah* should be carefully observed by ensuring the *ʿillah,* i.e. the cause of ruling. Further research is required to harmonize between the condition of DSD and the stages of *maṣlaḥah.* For example, Mohamed and Mohd Noor view salt-wasting CAH as an emergency state which requires urgent treatment. It is a severe form of 21 hydroxylase deficiency and if undiagnosed, symptoms of salt-wasting CAH will appear within few days or weeks after birth, and in some cases leads to death. It is true that this condition needs urgent treatment, but does this condition call for urgent surgical treatment? In this case, surgery may be elective and could be postponed because the most important treatment is to ensure aldosterone works well to retain sufficient sodium in the body. Urgent surgery is needed only if there is risk of infection in urine flow.

In view of the critical condition of malfunctioning gonads which are prone to malignant tumours; hormonal treatment can be used as a temporary alternative to delay the surgical treatment. As long as the risk is of serious complications has been confirmed to occur at later age, the surgery could be postponed to ensure that the patient is physically and emotionally ready for treatment.

[569] Mohd Salim Mohamed and Siti Nurani Mohd Noor, 'Islamic Bioethical Deliberation, p. 439.

Table 7: Relationship of Level of Maṣlaḥah, Types of Surgery and Their Appropriate Time

	Necessity	**Complimentary**	**Embellishment**
Faith	*-Not directly related to the discussion of surgical treatment.-*		
Life	Urgent surgery (to avoid imminent harm in life-threatening conditions).	Elective surgery (to restore fertility).	
Mind	*-Not directly related to the discussion of surgical treatment.-*		
Progeny		Elective surgery (to remove undesired gonadal tissue & to seek better functioning genitalia).	Cosmetic surgery (to gain better genitalia).
Wealth	*-Not directly related to the discussion of surgical treatment.-*		
	⇩	⇩	
	Appropriate for early surgery.	**Appropriate for later surgery.**	

In addition to clarifying prioritization of *maṣlaḥah* according to the element of 'strength', al-Būṭī continues to explain that when there are two overlapping benefits within the same 'strength', they should be analysed based on its 'prevalence'. That which benefits more people is prioritised over which that benefits only one person or a small group of people. Further explanation on this element, in its general context, can be found in subtopic 6.6, Chapter 6. However, in discussing the importance of surgery for patients with DSD, this factor is deemed not applicable for two reasons. Firstly, it is because the case itself refers to individual cases. Specific benefit, known as *maṣlaḥah khāṣṣah* is concerned with each unique case and thus is not concerned with the public benefits at large. Yet Ibn ʿAshūr argues that the benefits are intended for both public and individuals. The individuals' benefits are recognised within the *maṣlaḥah khāṣṣah* because by ensuring their benefits, the public interests are secured.[570] Secondly, if the public interests (i.e. the parental or the social expectations) are given more concern than the patient themself, it will diminish the rights of the minor patients to have better

[570] Al-Ṭāhir Ibn ʿAshūr, p. 280.

treatment based on the diagnosis and it will be detrimental for adult patients to participate in the decision-making process.

The third aspect of weighing the most imperative *maṣlaḥah* is to observe the 'implications'. Assessment of all treatments should be conducted to ensure empirical evidence of the quality of the treatment in the long and short terms. Analyses should be made of the surgical outcome and comparison should be made between early intervention and delayed intervention as well as the long-term results of non-operative intervention.[571] Data across geographical boundaries is essential to conduct the analysis. The establishment of registry-based research efforts, such as those of the European I-DSD/I-CAH and United States DSD-TRN, will provide important surgical and non-surgical outcomes.[572]

5.7. Treatment of Patients with Disorders of Sex Development (DSD) and *Khunūthah*

Based on the relationship between DSD and *khunthā*, the treatment of the patients with DSD is classified, as in Table 8. *Khunthā mushkil* (intractable *khunthā*) is seen as having the least number of cases due to the advancement of biomedical technology in identifying signs of dominant sex in most cases. In the absence of dominant signs, gender determination is perceived impossible. Therefore, the patients remain as *khunthā* and obliged to *fiqh khunthā* as long as the true sex is uncertain. The treatment for *khunthā mushkil* which is conducted to alleviate any harmful risks, is deemed to be recommended. However, sex assignment surgery is prohibited as it is unnecessary until the correct sex prevails. Double-effect treatment such as gonadectomy to avoid germ cell cancer risk will indirectly lower the testosterone level. That in turn cause non-development of male internal organs and leads to femaleness, such as gonadectomy, are not considered as sex-change treatment.

Meanwhile, the treatment for *khunthā wāḍiḥ* (discernible *khunthā*) is widely discussed by juristic councils and individual scholars in terms of its permissibility for obliterating

[571] M. DiSandro, D. P. Merke and Richard C. Rink, p. 327.
[572] Melissa Gardner and David E. Sandberg, p. 6.

sex ambiguity, restoring physiological and psychological health as well as ensuring fertility. The treatment is based on the recommendations of the medical experts following the diagnoses and identification of signs of the dominant gender. It includes both hormonal and surgical treatments as explained in the abovementioned. Given *maṣlaḥah* is used as the mechanistic tool for analysing the appropriate time for surgical intervention. In the event of life-threatening and critical condition, urgent surgery should be considered for minor patients. Otherwise, elective surgery should be conducted when patients are competent to be involved in the decision-making process.

Table 8: Deliberation of Treatment According to the Types of Disorders of Sex Development

Types	**Gender Assignment**	**Implication on Religious Obligations**	**Treatment**
Khunthā Wāḍiḥ	Gender assignment is identified based on the Islamic biomedical approach.	The person is subject to *fiqh* of *khunūthah* until the dominant gender is ascertained. As soon as the gender is determined, the person is subject to the rules according to the assigned gender.	Treatment is required to obliterate ambiguity, restore physiological and psychological health. Hormonal treatment is prioritized, if available, over surgical treatment. Timing for surgical treatment, if necessary, should be based on *maṣlaḥah.*
Khunthā Mushkil	Gender determination is perceived impossible. The evaluation could be carried out from time to time if there are any biological or physical changes.	The person is subject to *fiqh* of *khunūthah* until the dominant gender is ascertained. Then the person will be subject to the rules according to the assigned gender.	Sex assignment surgery is unnecessary until the appropriate signs of sex prevail to ascertain the dominant gender. Other required treatment is to be conducted to restore physiological and psychological health.
Non-*khunūthah* (Other types of DSD)	Gender remains as what was assigned at birth unless gender reassginment is required. The Islamic biomedical approach is used in the latter case for the correct-sex determination.	The person is subject to the rulings according to the (re)assigned gender. Thus, *fiqh* of *khunūthah* is not applicable in this case.	All required treatment is to be conducted to restore physiological and psychological health, and not subjected to the SAS. Timing for surgical treatment, such as gonedectomy, if necessary, should be based on *maṣlaḥah.*

Other conditions of DSD are treated to restore physiological and psychological health and are not subject to sex reassignment. For example, patients with CAIS who have clear female genitalia are not included in *khunthā*. Patients are normally reared as female but diagnosed with 46,XY at a later age. They can continue their normal life and their gender is recognised from their body and genitalia appearance. Surgery to remove the testis that exist due to 'Y' chromosome is permissible to prevent the risk of cancer. Sex reassignment is permissible only if harms are higher than the benefits of remaining in the sex assigned at birth.

5.8. Conclusion

Treatment is the most delicate aspect in the management of patients with DSD. It requires thorough assessment from the clinical aspect prior to any decision being made. Long-term research across time and geographical boundaries is required to assess the efficacy of the treatment and for its improvement. The implications vary from one case to another depending on the biological condition. Additionally, patients cannot be assessed immediately after treatment. The impact might be seen as much as 20 years later for those who undergo the treatment during infancy.

From the Islamic perspective, treatment is granted to restore one's health physiologically and psychologically. Muslim jurists have welcomed the advancement of biomedical technology to bring about better chances to identify and rectify ambiguous external genitalia. The deliberation encompasses the permissibility of a treatment with regard to the categories of *khunūthah* and DSD and most importantly to reflect current debates on timing of surgical treatment for minor patients. Thus, *maṣlaḥah* is proposed as a mechanistic tool to identify the need for surgical treatment, especially for infants and children, and extending to all DSD patients at large.

The recommendation of the treatment must not be without a decision-making process. Diagnoses, sharing information, discussions and consent are all required elements prior to treatment. In the next chapter we will further explore Islamic ethics in the decision-making process, particularly pertaining to the context of DSD.

6. DECISION MAKING PROCESS IN THE MANAGEMENT OF PATIENTS WITH DISORDERS OF SEX DEVELOPMENT (DSD)

6.1. Overview

Who can make a decision? What decision to make? These questions should be explored thoroughly in order to ensure the best practice for the management of patients with DSD in response to the second research objective, which is related to Islamic bioethical underpinnings of the decision making process. Therefore, this chapter will firstly discuss autonomy and competency in the context of medical history and Islamic outlook as well as characteristics of personal autonomy. This will lead to a deeper investigation of competent actors of decision making process by analysing approaches of medical decision making as portrayed in patient-doctor relationship. For a closer look, actors of decision making will be identified and a proposal of type of decision making in DSD's management will be presented at the end of this chapter.

Clearly, the main actors are the patients and the doctors. Patients who themselves carry the burden and bear the consequences, might choose the best that they can think of. The doctors who have capabilities and knowledge in handling such cases might provide the best recommendation of treatment. The types of the relationship between these two parties shape the decision being made. However, making the decision becomes more challenging when families play a great role in determining the best treatment for loved ones. Adding to the cultural context, some Muslims engage with religious leaders in making a decision that is seemed to consider on religious teachings even if they are practising their religion rarely.

The decision required in this management is pertaining to firstly, gender (re)assignment, e.g. what is the appropriate sex to be assigned; is sex reassignment required? Secondly, the treatments, e.g. is hormonal treatment adequate; when should sex assignment surgery should be done? A thorough discussion of both aspects has been discussed in Chapter 4 and 5 over what factors should be taken into account in assigning the correct gender and planning for medical intervention. The main discussion now shifts to who can decide. The following will explore the core element of decision making, i.e. autonomy in medical and Islamic settings, the actors

of decision-making, the type of decision-making process and its applicability in managing patients with DSD.

6.2. The Birth of the Notion of Autonomy in Biomedical Ethics

Issues of autonomy and informed consent always evolve around the context of decision-making. History records the dynamic progress of patient-doctor relationships over the years. Concern about medical expertise - within the relationship - has now shifted to the autonomy of the patients. The roles of doctors were and still are seen as a noble profession in helping out patients to alleviate the illness and to restore health. Traditionally, a doctor's status was assumed as next to God due to the ability to heal illnesses.[573] The term *al-ḥakīm,* which is simply translated as a wise person was also used to refer to a physician in the early literature such as in the translations of the books of Aristotle, Plato and Galen of Pergamum who were Greek physicians and philosophers.[574] Based on Hippocratic pledge, a doctor holds on his oath of, "I will use treatment to help the sick according to my ability and judgement, but will never use it to injure or wrong them".[575] This contributed to the paternalistic atmosphere. For centuries patients and doctors put their mutual trust to be treated and give treatment without question.

Today this practice is deemed to be unacceptable. Tom L. Beauchamp views it as an extremely disappointing history in terms of nondisclosure ethics and depreciation of patients' consent.[576] Some argue that the practice changed immediately after World

[573] Centers for Disease Control and Prevention, *U.S. Public Health Service Syphilis Study at Tuskegee*, The Tuskegee Timeline, 2018 (USA: U.S. Department of Health and Human Services, 2015) [Online] Available at <https://www.cdc.gov/tuskegee/timeline.htm> [accessed 30 November 2018]; Mohammad Yousuf Rathor, MS Azarisman Shah and Mohamed Hadzri Hasmoni, 'Is Autonomy is Universal Value of Human Existence? Scope of Autonomy in Medical Practice: A Comparative Study between Western Medical Ethics and Islamic Medical Ethics', *International Medical Journal Malaysia*, 15 (2016), 81-88, p. 82.

[574] Ibn Abī ʾUṣaybiʿah, Aḥmad Ibn al-Qāsim, *ʿUyūn Al-Anbāʾ Fī Ṭabaqāt Al-Aṭibbāʾ (Biographies of Selected Physicians)*, ed. by Nazār Riḍā (Dār Maktabah al-Ḥayāh, n.d.), pp. 85-113.

[575] Hippocratic Oath

[576] Tom L. Beauchamp was a Senior Research Scholar of the Kennedy Institute of Ethics. His expertise is on the human-subjects research, the place of universal principles and rights in biomedical ethics, methods of bioethics, Hume and the history of modern philosophy, and business ethics. In 1975, he joined the National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research, where he wrote The Belmont Report (1978). He received many prestigious awards such as Lifetime Achievement Award of the American Society of Bioethics and Humanities (ASBH) for his contribution regarding bioethics and humanities.

War II.[577] The history records that Nazi doctors conducted dreadful medical experiments over thousands of prisoners in the concentration camps including unsafe and lethal drug testing, without their permission.[578] These outrages led to the establishment of the Nuremberg Code of Ethics in 1947 and the notion of informed consent was born. It is stated in the very first part of the code that 'the voluntary consent of the human subject is absolutely essential'.[579]

Toni C. Saad rebuts Beauchamp's claim about the lack of patients' informed consent in the ancient era and not so distant time. He maintains that although the term is not spelt out in the Hippocratic Oath, it was practised in the sense of encouragement of appropriate information disclosure and patients were free to choose their doctors and to refuse treatment.[580] He also argues that the birth of informed consent is not completely in response to what happened in World War II, but it was also influenced by the natural development of enlightened thought. It was not until the late 1960s and early 1970s that civil society of the United States moved to protest against racism and discrimination especially among black people. The patients' rights were sought against this backdrop of social unrest. The movement was led by the National Welfare Rights Organisation (NWRO) whose members were among those had been deprived economically and socially. One of the main concerns that they struggled for was fairer access to health care and patients' rights in a hostile environment. In 1973, the first American Hospitals Association Patients' Bill of Rights was published in response to the movement. The *Bill of Rights* transformed the physicians' obligations or virtues to the rights of the patients. This was carried out in parallel with the development of the ethics of medical research.

The enlightenment for proper ethics of medical research involving human and animal subjects was sparked again in 1972. After 40 years the Tuskegee Study was conducted to record the history of syphilis among Negro males, it was found that the

[577] Mohammad Yousuf Rathor, MS Azarisman Shah and Mohamed Hadzri Hasmoni, 'Is Autonomy is Universal Value of Human Existence? Scope of Autonomy in Medical Practice: A Comparative Study between Western Medical Ethics and Islamic Medical Ethics', p.82.

[578] Nuernberg, *Trials of War Criminals before the Nuernberg Military Tribunals under Control Council Law no. 10*, (Washington: U.S. Government Printing Office, 1949). p. 181

[579] Nuernberg, *Trials of War Criminals before the Nuernberg Military Tribunals under Control Council Law no. 10*, (Washington: U.S. Government Printing Office, 1949), pp. 181-182.

[580] Toni C. Saad, 'The History of Autonomy in Medicine from Antiquity to Principalism', *Medicine, Health Care and Philosophy*, 1 (2018), 125-137, p. 126.

study deprived the rights of 399 males with syphilis for proper treatment even with the penicillin which was the drug of choice available in 1947. It was conducted without the consent of the participants and no choice of quitting the study was provided for them. The study was ordered to stop immediately. There followed a thorough investigation and compensation was made for the participants and their families through a programme called Tuskegee Health Benefit Program.[581]

The history justifies the importance of the permission and informed consent of patients as the core of authorization in clinical treatment and medical research.[582] No wonder in 1970s vigorous debates on autonomy, free will, self-regulation and those similar concepts came into the discussion. The term 'autonomy' was used in The Belmont Report published in 1978 by the National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research, United States.[583] The report emphasized three basic ethical principles, i.e. respect for persons, beneficence and justice. In deliberating the first principle, the report explains that there are two basic requirements in respecting persons. Firstly, a person should be treated as an autonomous agent and thus the autonomy should be acknowledged. Secondly, a person with diminished authority should be protected.

The word 'autonomy' is derived from the Greek *autos* (self) and *nomos* (governance, rule, law). This word originally referred to state governance. The Oxford Dictionary, for example, defines autonomous as 'having the freedom to govern itself or control its own affairs.'[584] The concept later extended to the individual sphere by maintaining the premise of 'governing itself'. The Belmont Report defines an autonomous person as "an individual capable of deliberation about personal goals, and of acting under the

[581] Centers for Disease Control and Prevention, 2015.

[582] There are other reported cases regarding misconducted research pertaining to the ethical issues of authorization. Read more historical background of the development of informed consent in L. Campbell, 'Kant, Autonomy and Bioethics', *Ethics, Medical and Public Health,* (2017); Ruth R. Faden and Tom L. Beauchamp, *A History and Theory of Informed Consent* (New York: Oxford University Press, 1986).

[583] The Commission was established following regulating the National Research Act (Pub. L. 93-348). The main roles are to identify ethical principles in conducting research involving human subjects and to produce a guideline in order to ensure any related research is conducted according to the principles. Read more in Department of Health, Education and Welfare, *The Belmont Report,* Ethical Principles and Guidelines for the Protection of Human Subjects for Research, (United States: US Department of Health and Human Services, 1978) <https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/read-the-belmont-report/index.html> [accessed 2 December 2018].

[584] *Oxford Paperback Dictionary and Thesaurus*, ed. by Maurice Waite and Sara Hawker, 3rd edn (New York: Oxford University Press, 2009), p. 57.

direction of such deliberation."[585] This definition is in harmony with Beauchamp and Childress' description of personal autonomy in their first edition of the *Principles*. This is not a coincidence as Beauchamp worked as a consultant for the Commission during production of the Belmont report, which gives him better ground for a further concrete explanation.[586]

Beauchamp and Childress illuminate the concept of personal autonomy as 'self-rule that is free from both controlling interference by others and from limitations, such as inadequate understanding that prevents meaningful choice.'[587] Michael Kühler and Nadja Jelinek echo the explanation as the one who 'decides and acts according to [his or] her own convictions, values, desires and such like and independent of unwanted internal and external influences.'[588] Whilst, an American philosopher, Marilyn Friedman defines autonomous into one word as 'self-determination'.[589] These definitions, at least, enlighten us about what constitutes personal autonomy.

6.3. The Characteristics of Personal Autonomy

The characteristic of personal autonomy encompasses a few elements including one's convictions, being free from interference and without having limitations. Above all, competency is the most important element. A person should be competent enough to express his or her own conviction. The person should be competent enough to ensure there is no coercion in making the decision. That person should be competent enough to access and comprehend any related information for the informed decision.

Beauchamp and Childress upgrade their '*Principles'* in the fifth edition by explaining the concept of competence in making a decision in a medical context. They describe competence as "the ability to perform a task".[590] It is a wide spectrum that differs from one task to another and from time to time. It depends on a person's abilities and on how those abilities meet such a decision-making task. It is very rare to judge a person

[585] Department of Health, Education and Welfare, 1978, para 11 of 44.
[586] L. Campbell, 'Kant, Autonomy and Bioethics', p. 4.
[587] Beauchamp, Tom L., Childress, James F., *Principles of Biomedical Ethics* (Oxford: Oxford University Press, 2001), p. 58.
[588] Michael Kühler and Nadja Jelinek, *Autonomy and the Self* (Netherlands: Springer, 2012).p. 2.
[589] Michael Kühler and Nadja Jelinek, *Autonomy and the Self,* p. 4.
[590] Beauchamp, Tom L., Childress, James F. *Principles of Biomedical Ethics*, p. 70.

as incompetent due to various degree of factors and relative to specific tasks. They mention that a person who is incompetent to decide on financial affairs may be competent to decide to participate in medical research.[591] Competency to make the decision is identified through the abilities of:

a. Understanding the material information.
b. Making a judgement about the information.
c. Intending a certain outcome.
d. Communicating freely their wishes to caregivers or the investigator.[592]

Thus, people with these abilities should be able to have their rights of autonomously making a decision and respect for their authority is highly expected.

In the absence of those four abilities, the person has less autonomous authorization and is considered as incapable to make a decision. For example, children who are the majority group of patients with DSD, people with mental disabilities, people with severe illness that limit their competency and people in severe restricted liberty such as prisoners. These groups of people, on the other hand, should be protected. They still have rights to have access to adequate information, and to have sufficient and appropriate treatment according to the ability of the government and support system of the community. This is of special relevance in developing countries like Malaysia and Indonesia.

An authoritative and competent person, therefore, is responsible for protecting the rights of incapable persons. The obligation falls in the same way as the government over a citizen and the parents over a child. Hugo Tristram Engelhardt explains this relation in an interesting way. Guardians, according to him are not the extension of other individual's freedom. Instead, he states that:

> "They may be in authority over their ward as a parent is over an infant by virtue of either having produced that individual or through some moral equivalent of indentured servitude that arises through a minor's receiving parental support while not seeking emancipation."[593]

[591] Beauchamp, Tom L., Childress, James F., *Principles of Biomedical Ethics*, p. 70.
[592] Beauchamp, Tom L., Childress, James F., *Principles of Biomedical Ethics*, p. 71
[593] H. Tristram Engelhardt, *The Foundations of Bioethics*, 2nd edn (New York: Oxford University Press, 1996). 301.

Another characteristic of autonomy is consultative autonomy. This would not be at odds when the concept is laid on its original form of self-governance. A government is composed of numbers of departments of the judiciary, legislative and executive that requires consultation. Even if the concept of self-regulator is extended to individuals, Friedman affirms that autonomy requires social context for its realization. It is due to five factors as follows:

a. Autonomous persons are differentiated selves of such societies who are the product of socialization where common identities and commitments are shared.
b. The competency of an autonomous person depends partly on the acquisition of learning through other persons.
c. Meaningful options are weighed partly as matters of the social conditions facing someone.
d. Persons in communities or groups may enjoy autonomy collectively.
e. Autonomy is competency in the very exercise of interpersonal engagement with others.[594]

The researcher views the notion of respect for persons also include the respect of one's personal decision or agreement in consultation with family members or people who surround them. It pinpoints the very concept of shared decision making. Current scholarship on complete autonomy in making decision regarding DSD seems to diminish the roles of close family. Whereas a family's support and courage are vital for the patients. Their endorsement and encouragement enable the individuals to be accepted among society so that they can live their life as others without any discrimination and stigmatization. This is not to say they have to abide by whatever the family wants and desires. However, consulting them at the onset of the process will create a better relationship and outcome in the long term.

In sum, the paradigm of biomedical ethics moves from creating a better professionalism of doctor, to accommodation of the rights of the patients. Their rights

[594] Marilyn Friedman, *Autonomy, Gender, Politics,* A Conception of Autonomy (Oxford Scholarship Online: University Press Oxford Scholarship, 2003) p. 16.

are secured in the notion of autonomy, which depends on a patients' competency in decision-making. On the other hand, the rights of incompetent persons are protected by other relevant competent person such as parents or guardians.

6.4. Competency and Autonomy in Islam

A similar focus of competency, in biomedical ethics, is provided in Islamic ethics. However, the classical ethos of Islamic teaching does not emphasize the aspect of competency in relation to personal autonomy. The very essence of the teaching is to ensure competency in the realization of performing one's religious duties and obligations. It refers to the translation of *Sūrah al-Zāriyāt*, verse 56 as: "I have only created jins and men that they may *serve* Me."[595] The command of 'serve' clearly shows the core of the tenet, i.e. to carry out the duties and obligations in all forms and situations as a Muslim. Allah continues: "Nor Sustenance do I require of them, nor do I require that they should feed Me."[596] The only objective of submission to Allah is to seek His happiness. As humans will be held accountable for our deeds in the Hereafter.

A number of verses of the Qurʾān and Ḥadīth point out the importance of carrying out the duties rather than seeking for one's rights. For instance, "If any do deeds of righteousness, be they male or female, and have faith, they will enter Heaven and not the least injustice will be done to them."[597] In a broader sense, by accomplishing the duties, a person is fulfilling both his/her rights and others'. Ignoring the duties will eventually be an injustice to him/herself and to other persons in relation to such obligations. Furthermore, every single human being is responsible for his/her own deeds and will not carry the burden of others' sins. This is expressed in *Sūrah al-Anʿām*: "… every soul draws the consequence of its acts on none but itself: no bearer of burdens can bear the burden of another."[598]

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[595] Translation of the Qurʾān in ʿAbdullah Yūsuf ʿAlī, *The Holy Qur´an Text, Translation and Commentary*, New Revised edn (Brentwood: Amana Corporation, 1989). *Sūrah al-Zāriyāt* (The Winnowing Winds), 51: 56.

[596] ʿAbdullah Yūsuf ʿAlī, *The Holy Qur´an Text, Translation and Commentary*, *Sūrah al-Zāriyāt* (The Winnowing Winds), 51: 57.

[597] ʿAbdullah Yūsuf ʿAlī, *The Holy Qur´an Text, Translation and Commentary*, *Sūrah al-Nisāʾ* (The Women), 4: 124.

[598] ʿAbdullah Yūsuf ʿAlī, *The Holy Qur´an Text, Translation and Commentary*, *Sūrah al-Anʿām* (The Cattle), 6: 164.

These encouragements to do one's duty do not limit Muslims to seek their rights on the occasion of deprivation. Every Muslims is urged to free themselves from any discrimination and intolerance. A Ḥadīth that later was adapted as an Islamic legal maxim remains relevant on its stand of "harm should not be inflicted, nor reciprocated."[599] But it goes back to the responsibilities of the guardians to diminish any discrimination as the Prophet says:

> "All of you are guardians and responsible for your wards and the things under your care. The Imam (i.e. ruler) is the guardian of his subjects and is responsible for them and a man is the guardian of his family and is responsible for them. A woman is the guardian of her husband's house and is responsible for it. A servant is the guardian of his master's belongings and is responsible for them.' I [Ibn ʿUmar) thought that he also said, 'a man is the guardian of his father's property and is responsible for it. All of you are guardians and responsible for your wards and the things under your care."[600]

Based on this Ḥadīth, scholars of Sunni schools of thought explain the concept of 'competency'. The responsibilities are carried out according to his/her own 'competency' (*ahliyyah*) in order to ensure the validity of such action or decision making. Competency or capacity could be receptive or executive. 'Receptive capacity' (*ahliyyah al-wujūb*) is a capacity of acquisition of rights for all human beings, which exist due to the ascertainment of 'the covenant of God' (*zimmah*).[601] The covenant is only attainable through every life. Hence every single human being in this world is eligible to acquire his/her rights. Take note of the term used to describe eligibility of the rights. Instead of using the word rights (or *ḥaqq* in Arabic), scholars remain focus on the obligations that need to be accomplished in order to fulfil the rights of others. In contrast, 'executive capacity' (*ahliyyah al-adā'*) refers to the ability of a person to carry out his/her duty where his/her words and acts have legal implications in the light of sharīʿah. The deliberation of this topic in most Islamic jurisprudence books emphasizes its application in financial transactions. Performing such decision in establishing one's rights can, by analogy, be presumed to be in a similar context.

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[599] Mālik Ibn Anas, *Muwaṭṭa'*, ed. by Muḥammad Muṣṭafā Al-ʿAẓamī, vol. 4 (Emirates: Mu'assasah Zāyd Ibn Sulṭan, 2004), p. 1078. Ḥadīth no. 2758, Chapter *al-Qaḍā' fī al-Marfaq*.

[600] Muḥammad ibn Ismāʿil al-Bukhārī, *Ṣaḥīḥ Al-Bukhārī*, ed. by Abū Ṣuhayb al-Karamī (Saudi Arabia: Bayt al-Afkār al-Dawliyyah, 1998), p. 179. No. Ḥadīth 893, Book Pertaining to al-Jumʿah. An authentic Ḥadīth.

[601] The covenant of God is reflected on the verse 172, *Sūrah al-ʿArāf* (The Heights) when God asked the Children of Adam concerning His existence as their Lord and they testified that Allah is their Lord. The covenant encompasses acknowledgment that God is the Creator, Cherisher and Sustainer, therefore human acknowledge their duty to Him.

Islamic scholars explain these two types of capacity in four human development stages. Firstly, the embryonic stage which is categorised under 'imperfect receptive capacity' (*ahliyyah al-wujūb al-nāqiṣah*) due to the embryos inability of 'acceptance' (*qabūl*) of certain transaction such as receiving a gift (*hibah*).[602] Some rights are established for a foetus such as in case of inheritance and will. On the other hand, a foetus cannot be held liable for rights owed to others and thus its condition is referred to as 'deficient executive capacity' (*ahliyyah al-adāʾ al-qāṣirah*).

The second stage is during infancy.[603] This is the earliest stage where DSD can sometimes be identified. Beginning at this stage, humans should be entitled to 'complete receptive capacity' (*ahliyyah al-wujūb al-kāmilah*). Any rights that could be fulfilled for the baby should be carried out for his/her benefit. For instance, a baby has rights to live healthily, therefore any illness should be well treated. In contrast, as no legal intellect is endowed at this stage, their acts and words have no legal consequences. They are not held liable to any obligations due to deficient executive capacity. Likewise, any verbal disposition or actions are not possible for the decision-making process. This rule also applies to other conditions such as an insane person and a sleeping adult as mentioned in the Ḥadīth:

> "The pen is lifted from three persons: the one who sleeps until he wakes, the child until he attains puberty and the insane person until he regains sanity."[604]

The third stage is the discernment (*al-tamyīz*) level.[605] The executive capacity is applied based on intellectual capacity and on discernment which is the ability to distinguish between good and bad. It is believed to be from the age of seven until the age of puberty. Children at this stage are eligible for 'complete receptive capacity'. Though, they are only eligible for 'imperfect executive capacity' (*ahliyyah al-adāʾ al-nāqiṣah*) due to limited reasoning faculty. They lack physical freedom and autonomy, i.e. they are still under parental control. Any performance of worshipping duties is

[602] Wahbah Al-Zuḥaylī, *Al-Wajīz Fī ʾUṣūl Al-Fiqh (A Compendium of Principles of Islamic Jurisprudence)* (Beirut: Dār al-Fikr, 1995) p. 94.

[603] Wahbah Al-Zuḥaylī, *Al-Wajīz Fī ʾUṣūl Al-Fiqh,* p. 95.

[604] Sulayman Ibn Abū Daud, *Musnad Abū Daud Al-Ṭayālisī,* ed. by Muḥammad ʿAbd al-Muḥsin Al-Turkī, vol. 1 (Egypt: Dār Hijr, 1999) p. 89. Ḥadīth no. 91. Ḥadīth ʿAlī Ibn Abī Ṭālib.

[605] Wahbah Al-Zuḥaylī, *Al-Wajīz Fī ʾUṣūl Al-Fiqh (A Compendium of Principles of Islamic Jurisprudence)* p. 97.

accepted because of the religious advantages gained from the practices. Children are only capable of concluding actions and transactions that are totally for their benefits like receiving gift or charity. Unfavourable transactions that are related to spending of their property are invalid regardless of their guardian's supervision. However, with the permission of their guardians, a transaction which partakes both benefit and loss such as selling and buying are acceptable.

This is to suggest that the guardian's roles are required in making a decision. But to what extent could a child's preference, of DSD treatment or choosing of correct gender, be taken into consideration? What is the tool to ensure the guardian's advice is not merely their blind preference rather that the decisions are for the benefit of the child?

A child will grow up and reach puberty. That takes the discussion to the fourth stage which is puberty (*bulūgh*) and prudence (*rushd*). A teenager who reaches puberty and accomplishes biological and mental development has complete receptive and executive capacity. He/She is permitted to be involved in any financial transaction, manage their own wealth as well as decide on other non-financial matters. Some scholars differentiate between puberty and prudence stages. Anyone who reaches puberty but does not attain the prudence stage is still under the supervision of the parents or guardians. For instance, a girl who attains menses – a sign of puberty as Islamic scholars point out – at age nine may still not be able to manage her wealth properly. Therefore, guidance from the parents is vital. This stage includes a person with learning and cognitive disability (*al-maʿtūh*) and unintelligent person (*al-safīh*).

On the other hand, a person who attains prudence stage has reached the optimum level of competency and is completely responsible for his/her own conduct and actions as well as free from guardianship. He/She has complete capability to decide on his/her own and carries responsibility.

The concept of 'capacity' provides a holistic parameter of to what extent one should give and take in term of rights and responsibilities resulting from his/her own decision. The credibility of making such decision requires one's eligibility and capacity. As a competent person, one may be a doctor, an adult patient, a minor patient, a

parent/guardian or a religious leader. The responsibility comes with liability, be it as a physician, patient or parent/guardian.

6.5. Guardianship

Although the explication is associated with stages of human development which indicate age factor, executive capacity is actually identified through cognitive ability. Those with limited capability e.g. children or impairment of cognitive ability will require support from a competent person in order to fulfil his/her receptive capacity. At all stages of growth, except at the prudence stage, the person is categorised under deficient or imperfect executive capacity which entails the need of parents' or guardians' roles in assisting decision-making.[606]

Wahbah al-Zuḥaylī (d. 2015), a contemporary Islamic scholar emphasises the roles of guardians (*al-waliy*), i.e., adult with complete competency over the persons with 'imperfect competency' (*al-qāṣir*) under the concept which is known as guardianship (*al-niyābah* or *al-wilāyah*).[607] Guardianship can be divided into two categories, namely, 'guardianship of person' (*al-wilāyah ʿala al-nafs*) and 'guardianship of property' (*al-wilāyah ʿala al-māl*). The latter is related to the roles of a guardian in saving and investing the property of the person with imperfect competency. Whilst the former is related to the roles of guardians in teaching and guiding moral values, providing and sustaining good health care, physical growth and education as well as supervision of marriage for *al-qāṣir*.[608] *Al-qāṣir* in this context includes a child, insane person and imbecile (*al-maʿtūh*).

The importance is to ensure that the rights of those persons, who are incapable of decision-making are well-protected. Ignoring their rights will lead to irresponsibility and harm that tarnish the *maqāṣid al-sharīʿah* of safeguarding the life and body and

[606] In Islamic juridical discourse, restrictions of legal competency (*ʿawāriḍ ahliyyah*) are divided into two, i.e. i) voluntary restrictions (*ʿawāriḍ muktasabah*) including ignorance, intoxication, errors, coercion and jest; ii) involuntary restrictions (*ʿawāriḍ samawiyyah*) including infancy, insanity, mental retardation, unintelligent, forgetting, sleep, loss of consciousness, terminal illness and die. Every restriction has its own impact on legal competency. The restrictions basically due to interruption of cognitive capability, temporarily or permanent. See further information in Wahbah Al-Zuḥaylī, *Al-Fiqh Al-Islāmiy wa Adillatuh (Islamic Jurisprudence and its Proof)*, vol. 7 (Damascus: Dār al-Fikr, 1985), p. 747.

[607] Wahbah Al-Zuḥaylī is a prominent contemporary scholar in Sunni school of thought.

[608] Wahbah Al-Zuḥaylī, *Al-Fiqh Al-Islāmiy wa Adillatuh,* p. 747.

avoiding any destruction. Hence, in the decision-making process, the role of parents or guardians over children or persons with cognitive impairment is vital within which the 'guardianship of person' is applied.

6.6. Is Personal Autonomy Relevant in Islamic Teaching?

The very basic underpinning of Islam towards human beings is clearly articulated in verse 70, *Sūrah al-Isrāʾ* on honour of the status of human over other creations.[609] The Qurʾān states that the honour granted by the Creator (Allah) covers all aspects as humanity is believed to be the best creation come into existence. They are given so many privileges such as to enjoy the life in this world and to benefit from other creations under the light of submission to the Nourisher.

The Qurʾān reiterates in a number of verses that human beings are endowed with everything created between the heavens and the earth. "And He has subjected to you, as from Him, all that is in the heavens and on earth: Behold, in that are Signs indeed for those who reflect."[610] *Taskhīr* is a well-observable concept of ecological relationship in which Divine subjugation of nature is rendered for mankind to ultimately recognize, acknowledge and glorify Allah. In contemplating the signs of the Creator, the utilization of nature reflects the freedom of management, governance and administration given to humanity under the supervision of Islamic moral and ethical aspects.

The uniqueness of the creation of human being is observed in the cognitive ability within which the freedom of thinking, managing, decision-making, regulating and executing are part and parcel of daily human life. The understanding of a person as an autonomous agent is acknowledged as every human being is inculcated to maximize the capability of reasoning, contemplation and making choices. The process requires searching for true knowledge prior to making the decision and taking action. The Qurʾān reminds: "and pursue not that of which thou hast no knowledge; for every act of hearing, or of seeing or of (feeling in) the heart will be enquired into (on the Day

[609] ʿAbdullah Yūsuf ʿAlī, *The Holy Qur´an Text, Translation and Commentary*, *Sūrah al-Isrāʾ* (The Night Journey), 17: 70.
[610] ʿAbdullah Yūsuf ʿAlī, *The Holy Qur´an Text, Translation and Commentary*. *Sūrah al-Jāthiyah* (The Crouching), 45: 13.

of Reckoning)."[611] Thus, autonomy is not an alien concept in Islam. It is the characteristics which comes with responsibilities and liabilities.

The context is clearly observed in the Ḥadīth below:

> "'Ata' ibn Abī Rabih said: Ibn Abbas said to me: May I show you a woman of Paradise? I said: Yes. He said: Here is this dark-complexioned woman. She came to Allah's Apostle (may peace be upon him) and said: I am suffering from falling sickness and I become naked; supplicate Allah for me, whereupon he (the Holy Prophet) said: Show endurance as you can do and there would be Paradise for you and, if you desire, I supplicate Allah that He may cure you. She said: I am prepared to show endurance (but the unbearable trouble is) that I become naked, so supplicate Allah that He should not let me become naked, so he supplicated for her."[612]

The woman was offered a choice of either unwavering endurance over the sickness or seeking for treatment. In the sense that every illness should be healed, legally referred to as permitted (*mubāḥ*) and not obligatory (*wājib*), this Ḥadīth purposely shows the process of decision making particularly in terms of the medical treatment. The Prophet himself did not exercise any compulsion towards this black lady. Rather she was given her own sphere of autonomy to make a decision. She bore the responsibility of her own decision and put effort to ensure her *ʿaurah* was covered.

However, realizing that every deed is conducted for the sake of Allah, 'complete personal autonomy' is inconsistent with the Islamic teaching. There are two reasons. Firstly, self-determination should be guided by the Divine revelation to ensure its constant benefit to the self and its surroundings in this world and the Hereafter. It is mentioned in the Qurʾān: "…Nor follow thou the lusts (of thy heart), for they will mislead thee from the Path of Allah…"[613] The objective of life is to achieve the highest purpose of sharīʿah in achieving *maṣlaḥah* through safeguarding the five principles; religion, life, mind, progeny and wealth in its dual methods of protecting them and avoiding harm.

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[611] ʿAbdullah Yūsuf ʿAlī, *The Holy Qur´an Text, Translation and Commentary*. *Sūrah al-Isrāʾ* (The Night Journey), 17: 36.

[612] Abu al-Ḥusayn Muslim Al-Ḥajjāj, *Ṣaḥīḥ Muslim (the Authentic [of] Muslim)*, ed. by Muḥammad Fuad ʿAbd Al-Bāqī, 2nd edn (Beirut: Dār al-Kutub al-ʿIlmiyyah, 1991). Ḥadīth no. 2576, *Kitāb al-Birr wa al-Ṣilah wa al-Adāb* (Book Virtue, Good Manners and Joining the Ties of Relationship) *Bāb Thawāb al-Muʾmin Fīma Yuṣīb bihi Min Maraḍ* (Chapter Reward for Believers Who are Inflicted with Sickness).

[613] ʿAbdullah Yūsuf ʿAlī, *The Holy Qur´an Text, Translation and Commentary*. *Sūrah Ṣad* (The Letter Ṣad), 38: 26.

The second reason that complete personal autonomy is impossible in Islam is because decisions should be carried out in the light of mutual benefit to the distinct self, i.e. the person themself, and toward other persons because all deeds are the manifestation of performing the responsibilities, which caters for both the obligations towards self and to fulfil the rights of others. If the exercising of autonomy is constructed merely on the ground of achieving one's rights, it will deviate itself from the context of socialization towards a limited space of individual lifestyle. Allah reminds Muslims that the believers are but brothers.[614] The Prophet also explains that: "The similitude of believers in regard to mutual love, affection, fellow-feeling is that of one body; if any limb aches, the whole body aches with fever and sleeplessness."[615] Therefore, a person does not have complete personal autonomy to decide on sex change, per say. Firstly, because he/she is subjected to the Divine law on the restriction of sex's alteration as discussed in Chapter 5. According to Asrorun Ni'am Sholeh, Secretary to Fatwa Commission, Council of Indonesian Scholars, individuals are responsible to protect their body due to the right of usufruct (*ḥaqq al-intifāʿ*) and they do not have ownership right (*ḥaqq al-tamlīk*) as the soul is belong to Allah.[616] Secondly, at the macro level, the decision would have an impact on human reproduction, progeny, social health, family and possibly community. Unguided personal desire will only go astray from the objective of sharīʿah to preserve the body and progeny.

Therefore, within the Islamic ethico-legal framework the execution of autonomy is guided by the Divine law as the main mechanism of accomplishing such duties in serving God. Limitation of individual cognitive capability in acquiring complete knowledge of the universe demands concrete guidance to ensure the benefit and to avoid any harm. Self-actualization and determination without guidance may lead to the slippery slope of gradually removing oneself from God consciousness to a selfish and secular world view.

[614] It is recorded in *Sūrah al-Ḥujurāt* (The Chambers), 49: 10.

[615] Abu al-Ḥusayn Muslim Al-Ḥajjāj, *Ṣaḥīḥ Muslim*, vol. 4, p. 1999. Ḥadīth no. 2586, *Kitāb al-Birr wa al-Ṣilah wa al-Adab* (Book of Virtues, Good Manners and Joining the of the Ties of Relationship), *Bāb Tarāhum al-Muʾminin wa Taʿāṭufihim wa Taʿāḍudihim* (Chapter There should be Mutual Fellow Feeling and Love and the Will to Help Each Other among the Believers). An authentic Ḥadīth.

[616] Asrorun Ni'am Sholeh, *Conversation with Taqwa Zabidi* (25 September 2017).

The recognized guidance for Muslims refers to the basic source of Islamic law, in which any decision should be in line with the commandments of Allah. Thus, five elements of *maqāṣid sharīʿah*, i.e. faith, life, mind, progeny and wealth should be protected and preserved from any harm. Besides, the public benefit should also be observed over individual benefit as noted in the Islamic legal maxim, 'specific harm is tolerated in order to prevent a more general one' (*yutaḥammal al-ḍarar al-khāṣ li dafʿ ḍarar al-ʿām*). Lastly, any evasive devices and destructive means should be blocked, while any means leading towards its goodness should be opened as Al-Qarāfī, (d. 1285) a Mālikī scholar advocates in his *al-Furūq*.[617] This is to ensure that the objectives of sharīʿah are preserved by all means that are available.

6.7. Patient-Doctor Relationship in Conventional Medical Decision Making

At this stage we have been exposed to the context of competency and autonomy in conventional and Islamic perspectives. While the former focuses on patients' rights, the latter does not specify who has autonomy in decision-making process. Going back to the meaning of autonomy and its character from both Islamic and contemporary perspectives, it denotes four components including:

a. Self-determination with optimum capability and competency.
b. Free from coercion and interference.
c. Free from limitations such as inadequate understanding.
d. Guided and governed by the objectives of sharīʿah.

The question who can decide remains unrequited. To elaborate this, we need to explore conventional medical approaches of decision-making over patient-doctor relationship. The patient-doctor relationship entails a few components either complementing or detracting from each other, such as individual religious belief and professional skills, cultural values and medical policies, medical terminologies and lay understanding, and autonomous decision and collective decision.

[617] Al-Qarāfī, Shihāb al-Dīn Aḥmad Ibn Idrīs, *Al-Furūq Anwār Al-Burūq Fi Anwāʾ Al-Furūq,* vol. 2 (Beirut: ʿĀlam al-Kutub, n.d.) p. 33.

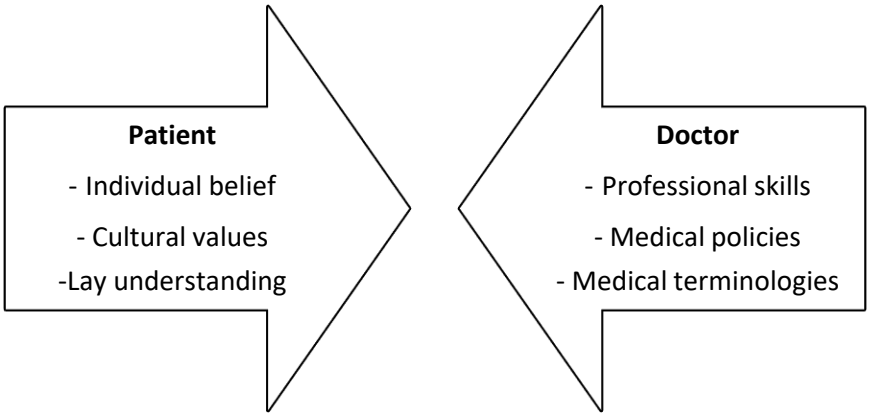

Figure 6: Elements of Patient-Doctor Relationship

As every individual is free to think, comprehend, and analyse every subject in this life, it will shape his/her own beliefs. As persons live together within communities, influenced by time and place, common beliefs will be translated into practices and slowly shape collective values among themselves and later become culturally adapted by the communities. The values embedded within the communities, on the other hand, may contribute to shaping one's thinking and belief. The more exposure one has of the knowledge and experiences of other cultures, the higher one's understanding and openness toward such situation. The fact is that these two elements are inseparable from oneself in dealing with others and making decisions.

The spectrum of understanding other peoples, cultures and religion within variable degrees, depends on various factors such as age, educational background, and socioeconomic factors. For example, *fast* or *fasting* might be understood differently by different people. An imam will take it as a religious obligation to abstain from all kind of foods and drinks during the day between dawn (*fajr*) and sunset (*Maghrib*). A strict devotee of Hinduism will quickly relate the word with *upavasa,* i.e. to stay or sit near to the Lord by abstaining from certain kinds of food only. Whereas a doctor advises a patient to perform a fast for a certain period of time, due to a requirement to get an accurate reading of a blood test. This is a simple example of how important communication is and understanding of specific terms between a patient and a doctor. A more complicated circumstance will affect the process of discussion when it comes to emotion, principles and beliefs.

On the other hand, some doctors hold their own religious beliefs and practice specific cultures. They must rely on their professional skills and ethics. During many years of the learning process and experience, they build up skills based on empirical knowledge, gained through research and observation. This shapes their professional credibility that undeniably enables the trust of patients in them. However, that intellect and status eventually set a distance between them and the patients. The distance is called by Engelhardt as a 'barrier' that could not be demolished by redistribution of knowledge in the way redistribution of wealth can overcome the gap between the rich and the poor.[618] The medical profession is often faced with needs that are not always in harmony with each other, for example:

a. Serving health care needs and individual's desires.
b. Supporting the health care needs and societal desires.
c. Performance of skills and arts as self-perpetuating.
d. Aiming at the acquisition of knowledge.
e. Engaging in the profession to gain income and prestige.

The challenge is higher in (a) and (b) goals in order to incorporate patients' wishes and local culture into the medical setting. The tension between patients and doctors can arise due to religious and cultural differences.[619] Hence, doctors are expected to professionally cope with the circumstance and adjust their attitudes and behaviour, whilst still providing the best clinical care to patients from various backgrounds.

Despite the concern about individuals' attitudes (be it the doctor's or patients), policies and procedures are at stake when they encounter cultural objections. Cultural awareness in medical teaching should not be limited to the largest community in a specific area but also the minority groups that made up the nation. Muslims that cover almost 23% of the world population demand high attention to Islamic values pertaining to medical ethics. As in the United Kingdom, Gatrad and Sheikh mention that a minimal awareness of Muslims' traditions is necessary for delivering the care that is culturally

[618] H. Tristram Engelhardt, *The Foundations of Bioethics*, p. 292.

[619] Culture refers to common practices and values upheld by the specific communities. In this sense, any culture which is believed to be based on Islamic teachings should be provable by the Divine revelation, *qiyās* or *ʾijmāʿ* in order to ensure the originality of commandments of Islam and to avoid any misconceptions. Occasionally, culture is mistaken for religious practice even by patients themselves.

sensitive.[620] Muslims in the United States also found that the Islamic bioethical discourse did not adequately meet the need of Muslim professionals, patients and religious leaders.[621] For countries with Muslim majority populations as in Malaysia and Indonesia, more dialogue on a universal bioethics framework is required to ensure its applicability at the local level. These scenarios show that the policies at the international and national levels should be revisited frequently in order to mitigate inflexibility and to ensure its harmony with the current practice.

Efforts have been made to include cultural studies into the medical curricular. Carla Bout in-Foster and her team suggest 'the professional culture of medicine' as a theoretical framework for medical students in New York.[622] This is a useful concept as it focuses on a physician's culture, or in other words their own culture related to medicine so that the students themselves will have a great exposure to the importance of cultural competence. Yet, the qualification and standardisation of medical ethics teaching in Southeast Asian countries, including Malaysia and Indonesia, according to a study conducted by Miyasaka and others, still requires further improvement.[623]

To analyse further the patient-doctor relationship, here are the approaches in a medical decision-making setting. The most applied patterns across time are introduced below.

6.7.1. Paternalistic

Paternalism is the most prevalent approach of decision making prior to 1980s. Its existence was identified in North America when physicians were acknowledged as the best advisor and decision makers, and the patient as a listener.[624] It is so called

[620] A. R. Gatrad and A. Sheikh, 'Medical Ethics and Islam: Principles and Practice', pp. 72-75.

[621] Aasim I. Padela, 'Islamic Bioethics: Between Sacred Law, Lived Experience and State Authority', *Theoretical Medicine and Bioethics: Philosophy Medical Research and Practice,* 34 (16 April 2013), pp. 65-80, p. 66.

[622] Carla Boutin-Foster, Jordan C. Foster and Lyuba Konopasek, 'Physician, Know Thyself: Professional Culture of Medicine as a Framework of Teaching Cultural Competence', *Academic Medicine,* 83 (2008), 106-111, p. 106.

[623] Michio Miyasaka and others, 'An International Survey of Medical Ethics Curricula in Asia', *Journal of Medical Ethics,* 25 (1999), 514-521, p. 520.

[624] Cathy Charles, Amiram Gafni and Tim Whelan, 'Decision-Making in the Physician-Patient Encounter: Revisiting the Shared Treatment Decision-Making Model', *Journal of Social Science and Medicine,* 49 (1999), 651-661, p. 652.

because depicting a parent-child relationship in which the parent (physician) is seemed to have the right to decide the best for the child (patient) even if the child disagrees. A research conducted by Cathy Charles and others point out that there are a few underlying assumptions to the dominant roles of the physicians. Among others, two are mentioned here. Firstly, with regard to the existence of a single best treatment for almost all illnesses, and for that the physician is well equipped with the knowledge of current clinical assessment. The physicians consistently apply the medical information when selecting treatments for their patients. Secondly, doctors are also expected to be in the best position to evaluate preference between available treatments and to decide the most appropriate one.[625]

This is a one-way method of delivering the information, i.e., from the physician to the patient. The autonomous sphere of the patient is very minimum. The physician could be that particular physician who is supplying the treatment or might be in consultation with other related physicians. All information such as natural history of the disease; the benefits and risks of the various treatment alternatives; description of the treatment's procedure; and available information and resources within the community are conveyed to the patient. This approach is highly linked with the passive behaviour of patients who are likely to listen more than to express their circumstance, feelings and information that they hold.

There has been a decline of this approach in many parts of the world, but it remains observable in Southeast Asia. This phenomenon has been associated with cultural practices in the area's own accepted communication pattern, although there is evidence that both physicians and patients would like to switch to a partnership or shared style of decision making – that will be discussed shortly.[626] Mora Claramita and others report that in Indonesia the unintended social gap occurs due to several factors such as firstly, high respect towards elders or people with higher social status.[627] This ambience is reflected in the second factor of maintaining harmony and positive

[625] Cathy Charles, Amiram Gafni and Tim Whelan, 'Decision-Making in the Physician-Patient Encounter: Revisiting the Shared Treatment Decision-Making Model', p. 652.

[626] Elizabeth Murray and others, 'Clinical Decision Making: Physicians' Preference and Experience', *Biomedical Central Family Practice*, 8 (2007).

[627] Mora Claramita and others, 'Doctor-Patient Communication in Southeast Asia: A Different Culture?', *Advance in Health Sciences Education,* 18 (2013), 15-31, p. 29.

etiquette by the adherence to non-verbal politeness. Thirdly, it is due to superficial accord prior to the discussion, rather than establishing an open and long-term relationship. Fourthly is related to the social norm that allows informal individually modified interpretations and fifthly, a tendency to show diffidence and hesitation.[628] In addition, a strong family support system or communal system contributes to this phenomenon. This final factor will be described later in the fourth approach of decision making.

As Indonesia shares common cultural values with Malaysia and Singapore, it is assumed that similar contexts can be found in those two latter countries. In researcher's experience these phenomena are certainly present in Malaysia. The Malay community, as described by Ani Amelia Zainuddin, an Associate Professor and practitioner of Paediatric and Adolescent Gynaecology at the National University Malaysia Medical Centre, describes the Malay community as being introvert and reticent and worrying about being humiliated. These factors discourage Malays from seeking treatment for DSD.[629] Zainuddin argues that the prevalence of those who are suffering from gender issue in Malaysia might be more than 5% that she found in her study.[630] This has adverse effects on of the norms of respectfulness and adherence to politeness, leading to unfinished decision making. In an interview with Rahmah Rasat, a paediatric endocrinologist at the same tertiary hospital, she mentioned that:

> "Sometimes we find parents in Malaysia who are not frank, and not very open to talk about how they feel, throughout the discussion. At times, they already have their own preference for having a son. When we discuss, tell them the diagnosis and recommend something opposite, they do not object but just nod their heads. Suddenly, they just drop off the follow-up treatment and do not come back."[631]

If this demeanour of reserve is maintained in making the decision about gender ambiguity, wrong outcomes may prevail and patients themselves will bear the consequences in their lives in the future. The recommendation of optimal gender policy proposed by John Money as described in the previous chapter, i.e. to confirm the sex

[628] Mora Claramita and others, 'Doctor-Patient Communication in Southeast Asia: A Different Culture?', p. 19.

[629] Ani Amelia Zainuddin, *Skype Conversation with Taqwa Zabidi* (20 July 2016).

[630] Ani Amelia Zainuddin, 'Outcomes of Female Patients with Congenital Adrenal Hyperplasia in Malaysia' (PhD, The National University of Malaysia, 2014), p. 268.

[631] Rahmah Rasat, *Telephone Conversation with Taqwa Zabidi* (1 August 2016).

of rearing through surgical intervention before 18 months is a kind of paternalistic approach. However, the patients bear the damaging consequences afterwards if pre puberty decision was wrong. Hence, parents and families of minor patients should play active roles in decision making to avoid DSD cases living in limbo.

6.7.2. Consumerism

Consumerism or informed decision making is another one-way relationship pattern. The physicians explain all required information about the patients' condition, various available treatments and their benefits, and potential risks. The very crux of this model is that the physicians are expected not to go beyond the boundaries of medical or scientific explanation.[632] Further action relies on the patients to process the information and to have their own informed choices and to make an informed decision. This model meets the concept of personal autonomy, where the patients have their own sovereignty to choose and decide the most preferred treatments. The underlying assumption is that the preference of physicians may not be the same as the patients' interest. Therefore, the physicians do not have any investment in the decision made. It seems that in such cases, they do not hold the responsibility and liability for any negative consequences thereafter.

Nevertheless, this model challenges the professionalism of the doctors, in which the clinical experience and knowledge have been assumed to be the essential skills that they have to offer.[633] The physicians who conduct numerous research project on their speciality will always want to propose the most recommended treatment, according to the patients' conditions particularly with DSD cases where normally people are unfamiliar with the medical terminologies and complex procedure. On the other hand, the boundary sets for the physicians may add another burden to the patients and their family who are then obliged to settle a very crucial decision for life. This approach may be overlapping with the next approach especially at the end of the process whenever patients' or families' preferences prevail.

[632] Cathy Charles, Amiram Gafni and Tim Whelan, 'Decision-Making in the Physician-Patient Encounter: Revisiting the Shared Treatment Decision-Making Model', p. 657.

[633] Cathy Charles, Amiram Gafni and Tim Whelan, 'Decision-Making in the Physician-Patient Encounter: Revisiting the Shared Treatment Decision-Making Model', p. 657.

6.7.3. Shared Decision Making

The limitations of paternalistic and consumerism approaches caused a switch away from those patterns to a shared or partnership decision making, during the 1980s. In 1979, Beauchamp and Childress proposed a set of philosophical principles in biomedical ethics and ideas started to evolve and to be challenged. This concerns and processes are still featured in present bioethical discourse.[634] As is abovementioned, one of the principles of decision making is autonomy. This principle opposes the paternalistic approach in the sense that the patients themselves are the ones who are faced with the consequences of their own decision. Thus, their participation in decision making would have a great impact on the outcomes rather than just undertaking the physicians' recommendations. Realising this need, for example, the UK government has started the campaign of Liberating the National Health Service (NHS). Shared decision making becomes the norm with the tagline: *no decision about me without me.*[635]

Shared decision making implies that physicians and patients play significant roles throughout the process. This two-way communication requires active participation and exchanging information by both parties. The physicians should inform the patients of all relevant information such as the available treatments and their alternatives; the benefits, the risks and the potential risks to the psychology and social well-being.[636] On the other side, the patients must express their thoughts, preferences, values and beliefs with regard to their illness and treatments. This approach entails time and cost consumption because the discussion may take a longer period of time to have both parties engaged. Besides, available information should be disseminated within the society so early awareness of DSD could be nurtured, giving prompt ideas to the patients of the issues that might arise depending on their circumstances.

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[634] Beauchamp, Tom L., Childress, James F., *Principles of Biomedical Ethics* p. 57. Among literature that challenges the concept of 'Principlism' are Abdallah S. Daar and A. Khitamy, 'Bioethics for Clinicians: 21 Islamic Bioethics', *Canadian Medical Association Journal*, 164 (2001), pp. 60-63.; Dana J. Lawrence, 'The Four Principles of Biomedical Ethics: A Foundation of Current Bioethical Debate', *Journal of Chiropractic Humanities,* (2007), pp. 34-40.; Mohammad Yousuf Rathor and others, 'The Principle of Autonomy as Related to Personal Decision Making Concerning Health and Research from an Islamic Viewpoint', *Journal of Islamic Medical Association of North America*, 43 (2011), pp. 27-34.

[635] US Department of Health, Education and Welfare, *The Belmont Report*, p.3.

[636] Cathy Charles, Amiram Gafni and Tim Whelan, 'Decision-Making in the Physician-Patient Encounter: Revisiting the Shared Treatment Decision-Making Model', p. 654.

Decision aids could be used to convey the message, ranging from high technology interactive videos to low technology flip charts with audio tapes. An education aid would hope to enhance the relationship building between the physicians and the patients enabling them to get to know each other and to understand how far they can work together.[637] In a BBC statement published on 12 October 2017, some observations were made about Great Ormond Street Hospital for Children (GOSH), NHS Foundation Trust in the United Kingdom.[638] This hospital is the largest paediatric centre in Britain and has the widest range of specialists for children's health in the United Kingdom. DSD is one of the major concerns in this hospital. Yet, the report said, there was a lack of take-home information for parents of DSD patients and it raised doubt about whether the parents had made informed decision. It doubted that parents had been given enough knowledge about the treatment and its results to give informed consent.[639] This report highlights the importance of decision aid in order to achieve a solid viewpoint.

Ranjini Ambigapathy and her colleagues conducted research to observe the Malaysian preference in decision-making patterns. It was found that the majority of the respondents preferred autonomous roles in decision making; challenging the general views of the Southeast Asian pattern being the paternalistic approach.[640] The preference of style seems to be associated with the rate of household income. Patients with lower household income passively rely on the physicians' recommendations of treatment as they believe that the physicians are at the best position to make the decision.[641] This research was conducted in an urban area i.e. Kuala Lumpur, the capital city of Malaysia. Though, socio-demographic data shows that the patients who attend the clinic are not necessarily among elite society, they are highly educated people with blue-collar jobs which have always been associated with urban lifestyle. Currently, there is no valid evidence to show the association between urban lifestyle

[637] Cathy Charles, Amiram Gafni and Tim Whelan, 'Decision-Making in the Physician-Patient Encounter: Revisiting the Shared Treatment Decision-Making Model', p. 655.

[638] Faye Kirkland, *Great Ormond Street Hospital Failing Intersex Children,* <http://www.bbc.com/news/uk-41593914> BBC News, 12 October (United Kingdom: BBC, 2017) [accessed 13 October 2017].

[639] Faye Kirkland, 2017.

[640] Ranjini Ambigapathy, Yook Chin Chia and Chirk Jenn Ng, 'Patient Involvement in Decision Making: A Cross Sectional Study in a Malaysian Primary Care Clinic', *BMJ Open*, 6 (20015), 1 - 7.

[641] Ranjini Ambigapathy, Yook Chin Chia and Chirk Jenn Ng, p. 4.

and being open discussion. Studies with a higher sample size of patients with DSD, may help us to understand better the factors that encourage patients' preferences of shared decision making.

Shared decision making approach could have a fruitful impact, yet it is a complex and challenging pattern. The patients come to the table of discussion with their own beliefs and values. These elements may act as filters in processing the information they received, hence the intended message may be lost, altered or transformed.[642] Besides, in a larger context, the partnership approach may also involve not only the treating physicians and the patients but also other related physicians and family members. The higher the number of participants, the greater the coordination required to tailor the preferences of all important parties.

6.7.4. Family Centred Decision Making

Family Centred Decision Making is very common in a hospital when an incapable, patient is admitted in medical crisis. The circumstance of the patient requires the doctor to speak to the next of kin regarding the diagnosis and/or the prognosis. Consequently, the discussion with the family persists beyond the intended period. In another scenario, a patient normally comes to the hospital with his/her family. Realizing the burden of the illness that the patient will bear, the family manages to elicit a promise, from the doctor, not to tell the patient the serious nature of the illness they have. Hence again, the discussion continues with the family about any decision that needs to be made.

The central point of decision making is informed consent. To achieve this, an informed decision should be attained. However, in these two instances, the patient has very little information on his/her circumstance and that denies her/him the autonomy to make a decision for themself. Therefore, Benjamin Freedman strongly argues for offering the truth to the uninformed patient.[643] He does not reject the pattern of family

[642] Cathy Charles, Amiram Gafni and Tim Whelan, 'Decision-Making in the Physician-Patient Encounter: Revisiting the Shared Treatment Decision-Making Model', p. 656.

[643] Benjamin Freedman, 'Offering Truth - One Ethical Approach to the Uninformed Cancer Patient', *Archives Internal Medicine,* 153 (1993), 572-576, p. 575.

centred decision-making model, but adopts the pattern with a very important adaptation, i.e. offering the truth to avoid any concealment.

The family decision model always misinterpreted as diminishing the autonomy of the patients. However, the autonomy remains relevant when the patients themselves are well understood of the health problem and defers the care to the family to act appropriately. Patients should always be offered enough knowledge to understand their conditions at whatever level of information they would like. That will preserve the autonomy of the patient to choose their own path thereafter. The researcher argues that it is an extension of shared decision making model whenever the decision is consulted, not only with the physicians, but with the family on the patients' agreement.

In certain cultures, it is common that the patients leave the medical discussion in the family's hands. In most Asian countries, an informed decision is not an individual determination.[644] Rather, it is a family's agreement on delicate issues. Medical intervention comes into that category. The successful decision that may be identified with a higher quality of life (QOL) for the patient also depends on family support that culturally is inhibited in Asian countries. The family is the fundamental unit of a society and individual is a fundamental unit of a family.

The Chinese community, for example, is strengthened with the 'Confucian virtue of benevolence (*ren*), reaches out in love to protect the best interests of family members'.[645] In Singapore, a multiracial and multicultural country, a study at an oncology ward was conducted for a 12-month period in 2001. The survey indirectly shows shared decision making model was transformed to a family-centred decision-making model because the Chinese are the predominant race, followed by Malays.[646]

Malays, the indigenous group of Malaysia and Indonesia particularly emphasize family roles in decision making. Malaysian Malays who are associated with Islam by law – as

[644] Michael F. Back and Chan Yiong Huak, 'Family Centred Decision Making and Non-Disclosure of Diagnosis in a South East Asian Oncology Practice', *Psycho-Oncology,* 14 (2005), 1052-1059, p. 1058.
[645] Deng Rui, 'A Family-Oriented Decision-Making Model for Human Research in Mainland China', *Journal of Medicine and Philosophy,* 40 (2015), 400-417, p. 406.
[646] Michael F. Back and Chan Yiong Huak, 'Family Centred Decision Making and Non-Disclosure of Diagnosis in a South East Asian Oncology Practice', p. 1052.

delineated in its Federal Constitution – are identified to a large extent as influenced by the Islamic viewpoint on the Qurʾanic verdicts on the patrilineal system. A parent's role in adult patient is as important as in minor patient cases. The institution of family is strong; members are intrinsically linked with every individual's life.[647] Their decision should not be seen as contrary to the patient's decision.

The same trend is identified in other countries with majority Muslim communities. In the case of DSD, we saw in subtopic 4.3.3, Chapter 4, on how religio-cultural factor is considered in gender assignment approach. This factor is particularly provided by the family, who sees this aspect is more important in response to the social expectation. Some of the cultural norms intertwine with Islamic teachings that shape the fabrication of what is called 'Islamic practices'.

6.8. Actors in the Decision-Making Process of Disorders of Sex Development

The approaches of medical decision-making process show that the actor is not only patients as presented in discussing autonomy in conventional perspective. Paternalistic approach suggests doctors as the main actor. But this is refuted on autonomous basis. Conversely, consumerism suggests patients as the actor. Whilst current trend of shared or partnership decision-making implies equal opportunity to both patients and doctors. The actors are then extended to family's roles in family centred decision-making model. Nonetheless, in the management of Disorders of Sex Development, the actors encompass patients, doctors, parents and religious leaders. In-depth interviews have been conducted among medical experts in DSD and Islamic scholars with regard to the multidisciplinary team of managing patients with DSD, as will be elaborated further in the next chapter. Throughout the conversations, the researcher identifies the respondents' views on the actor of decision making. Among the items in the questions of the semi-structured interview with Islamic scholars were:

a. Who has the autonomy of making the decision?
b. Does a parental decision over the minor patients infringe their rights?

[647] Mohammad Yousuf Rathor, MS Azarisman Shah and Mohamed Hadzri Hasmoni, 'Is Autonomy is Universal Value of Human Existence? Scope of Autonomy in Medical Practice: A Comparative Study between Western Medical Ethics and Islamic Medical Ethics', p. 86

These questions posed to them knowing that there are several aspects from Islamic underpinning that are related to the practice of decision-making processes such as guardianship, autonomy for indeterminate *khunthā* and the role of Islamic authority. Indirect questions were put to medical practitioners, realizing that the standard practice of consultation with patients and parents and the requirement of informed consent.

It should be noted here that thorough interviews should be conducted with a sufficient number of respondents, among medical practitioners to analyse the reality of their beliefs and practices with regard to the decision-making process. As this research focuses only on the theological aspect of the Islamic tenet, the responses gathered is only to show the overview of the practice for further discussion. The data cannot be generally applied in the wider context. The responses are shown in Table 9.

The findings are discussed on three scopes, namely the actors; approaches of decision-making and the issue of parental decision over minor patients. Based on the first scope, the researcher found out patients are the least mentioned as the decision maker. Doctors (indicated in the table as MP: medical practitioner) do not propose for them to be the decision makers, but one Islamic scholar (indicated in table as IS: Islamic scholar) sees an adult patient as having autonomy to choose the preferred gender in case of intractable *khunthā*. The second actors are doctors which is seen as the most mentioned actor during the conversation. It shows that the role of the doctors is unarguably important in decision-making process, let alone in DSD cases. Three Islamic scholars mentioned that doctors' roles are important for medical recommendations or management over issues on gender assignment and treatments for the patients. While two others acknowledge them not only as one of the actors but also as the expert and authoritative body who are responsible to handle DSD cases.

The third actors are parents. Many of the respondents of both Islamic scholars and medical practitioners highlight the roles of parents specifically for minor patients. This is an expected response from medical practitioners because most of them are paediatricians of various sub-specializations who deal with minor patients or underage patients. Thus, dealing with parents or guardians is vital. The fourth actors are religious leaders. In our previous discussion on the patient-doctor relationship, this actor is never been discussed. However, both groups of respondents suggested that religious

leaders' roles are essential. For Islamic scholars, the roles of religious leaders are required to verify recommendations made by the doctors. The recommendations here include gender assignment and types of treatments for the patients. It is significant with the discussions in Chapter 4 and Chapter 5 in which Islamic underpinnings are the major concern in managing Muslim patients with DSD. It was interesting to find out that most doctors welcome the role of Islamic scholars in the decision-making process. One of them mentioned that religious leaders are responsible for the social supports of counselling and rehabilitation. This indicates that their roles are required as supporting mechanism rather than providing input for gender assignment or the treatment. Whereas others welcome their roles throughout the process of decision-making, including one response that mentioned specifically their roles are important in dealing with cases of intractable *khunthā.*

The second scope is with regard the type of relationship between the actors. Some respondents just focus on single actor and that does not indicate any type of relationship. For example, the second Islamic scholar focuses more on the responsibility of doctors to make decision on gender assignment. He supported his argument with verse 7 in *Sūrah al-Anbiyāʾ* to ask those who poses knowledge when we have little knowledge on certain things. Another Islamic scholar who was Singapore's Mufti left the decision-making in the hands of medical authority. Besides, one of the medical practitioners just focus on the religious leaders to provide social support, despite her own responsibility as a doctor.

Only one respondent of Islamic scholar proposed for consultation among all related parties. Although he did not list members of consultation team, he hoped for establishment of professional management team in hospitals with the involvement of doctors and religious officers in managing the patients. Other respondents do not mention types of relationship between the actors. But they were more inclined towards partnership pattern when they alluded to the involvement of religious leaders in the decision making process made by the doctors or Ministry of Health with or without parents' roles.

The third scope is the parental decision over a minor patient that seems to be an infringement of child's rights. Three of the Islamic scholars view that the parental

decision indicates their active role as the guardian (*al-waliy* or *wilāyah al-abdāl*) and custody (*al-ḥāḍin*) over the child. Meanwhile, another couple of respondents consider a decision made by parents before the child achieves puberty to be over-ruling the rights of the child. One of them stated that doctors, parents and religious leaders hold no rights for minor intractable *khunthā* to have medical intervention before puberty. This is in line with the second respondent's view that any surgical intervention should only be conducted after puberty to ensure that all signs of dominant gender, as presented in Chapter 4, are prevailed. This is also important for intractable *khunthā* because any surgical intervention is futile if it is conducted without firstly identify the signs of dominant gender.

The interviews did not highlight the importance of patients' autonomy in decision making. Instead, the roles of three other actors were emphasized. How does Islam view this aspect in balancing the roles of *ahl al-khibrah* (the experts), parents and *ʿulamāʾ* (Muslim scholars) without neglecting the patients' voices? The following discussion will elaborate further on this topic.

Table 9: Actors in the Decision-Making Process Regarding Disorders of Sex Development and Issue on the Child Rights

Respondent	**Actors in the Decision-making Process**				**Child rights and observations**
	Patient	Doctor	Parents	Islamic scholars	
IS1	No specific but through consultation.				Not mentioned.
IS2		Responsible.			Not mentioned. Postpone treatment until puberty.
IS3	Indeterminate *khunthā* (adult patient): Has the right to choose their gender.		Responsible for the minor patient.		Not infringed by parental decision due to responsibility of guardianship for a child (*wilāyah al-abdāl*).
IS4		Responsible for medical recommendation.	Responsible.	Responsible to verify the recommendation of the doctor.	Doctor, parents and Islamic scholars hold no rights of decision making for minor intractable *khunthā* before puberty.
IS5		Responsible for medical recommendation.		Responsible to verify the recommendation of the doctor.	

Respondent	Actors in the Decision-making Process				Child rights and observations
	Patient	Doctor	Parents	Islamic scholars	
IS6		Responsible for medical management.	Responsible as the main player for minor patient but the role is not absolute.		Infringe the child rights if the surgical treatment is carried out before the puberty.
IS7	Within the jurisdiction of the medical authority. No comment from the Islamic point of view.				
IS8		Responsible as the expert and authoritative body.	Responsible for the minor patient.	Responsible for a legal decision in the case of two or more conflicting decisions.	Not infringed due to the responsibility of guardianship (*wilāyah*) and custody (*ḥaḍānah*).
IS9		Responsible as the expert and authoritative body.	Responsible for the minor patient.	Responsible for a legal decision in the case of two or more conflicting decisions.	Not infringed due to the responsibility of guardianship (*wilāyah*) and custody (*ḥaḍānah*).
IS10	Within the jurisdiction of the Ministry of Health and Islamic Council.				
MP11				Responsible for social support of counselling and rehabilitation.	

Respondent	Actors in the Decision-making Process				Child rights and observations
	Patient	Doctor	Parents	Islamic scholars	
MP12		Responsible.	Responsible for minor patient.	Responsible for Muslim patient.	
MP13		Responsible.	Responsible for minor patient.	Responsible for Muslim patient.	
MP14		Responsible.		Responsible.	
MP15		Responsible.	Responsible.		
MP16		Responsible.		Responsible for intractable *khunthā* cases.	

*Further details of the respondents can be found in Table 1, subtopic 1.6.1.1 (List of respondents).

6.9. Evaluation of Actors' Roles in Decision-Making Process

6.9.1. Patients

The respondents did not propose for patients to be the decision maker. The doctors were aware of the requirement of having informed consent from the patients prior any medical intervention, while the Islamic scholars emphasize that the adult patients with intractable *khunthā* should be given opportunity to decide their preferred gender in case of dominant gender is feeble.

The patients can be categorized into the adult and minor patients. Adult patients are those who experience the abnormal sexual development during childhood, but it was either undiagnosed or left untreated; or those who experienced atypical development only at a later age. A number of reports show that adult patients with DSD find it is hard to be involved in a romantic relationship, which caused distress as they are not able to meet the social expectation of marriage. The reason is because they are reluctant to disclose their condition and they are doubtful of the partner's response.[648] Many reports also indicate that the adult patients suffered depression and stigmatization due to the uncertainty of their sex and cross-gender behaviour role throughout their upbringing. This leads to the belief that they have the right to make the decisions based on their own bodily change. Although in a number of cases, gender change at a later age causes more depression, rejection and withdrawal from social activities.

Minor patients are those children diagnosed with DSD at an early age. They are recognised with DSD through various symptoms or signs such as abnormal genitalia or salt wasting syndrome. As the parents took responsibility for making the decision of gender assignment for their children, a number of patients expressed dissatisfaction with the treatments and their outcome when they grew up. Their grievances included problems with sexual function, mis-assignment of gender and the posttraumatic symptoms and depression they faced throughout their life. This happened perhaps due to previous technology of gonadectomy and genitoplasty (the terms were briefly

explained subtopic 5.3, Chapter 5) over the past 50 years which was assumed to be the best treatment for the children affected at an early age. The irreversible procedures of both surgeries critically affect the children if their sexual development is discordant with the assigned gender. However, since minor patients are incapable of making the decision, their life outcome depends on the parents and the doctors. This raises a concern of whether the parental decision infringes the rights of the children as it is made without their permission.

Supposedly, patients should be both respected and supported. They should not 'be left alone' as Engelhardt mentioned, in order to respect his/her personal sphere.[649] Patients have carried the burden of the illness or impairment. In any case, they should not bear the responsibilities of making the decision in isolation. A collective decision will disperse the burden, avoid futile recommendations, hence, negative consequences. Adult patients with complete executive capacity, depending on their physical and cognitive ability at the time of sickness, should have been given access to acquire information related to their circumstances. Although complete personal autonomy is not appropriate in Islam, that does not restrict individuals from providing an informed consent of the treatment. It is clearly mentioned in the Qurʾān "… make not your own hands contribute to (your) destruction; but do good; for God loveth those who do good."[650] This is one of the Qurʾanic verses that denotes the importance of making informed decision to avoid any futile or wrong action. In contrast, minor patients are those children with imperfect executive capacity. Their consent and decision depend on parents or guardians to safeguard their well-being and health.

Special reference is made for *khunthā mushkil* (intractable *khunthā*). Remember we have classified the patients with DSD into three groups as explained in Chapter 3. They are DSD patients without genital ambiguity, *khunthā wāḍiḥ* and *khunthā mushkil* – whose signs of dominant gender is ambiguous. The latter, according to Muslim scholars have the autonomy to choose their own appropriate gender since the dominant gender is indeterminate, due to equal strength of observable signs. The last resort is to observe the patient's sexual inclination as have been discussed in Chapter

[649] H. Tristram Engelhardt, *The Foundations of Bioethics*, p. 288.

[650] ʿAbdullah Yūsufʿ Alī, *The Holy Qur´an Text, Translation and Commentary*. *Sūrah al-Baqarah* (The Heifer), 2: 195.

4. However, with the development of innovative technology, it's highly anticipated that most cases of *khunthā* could be determined and thus this category falls under the classification of *khunthā wāḍiḥ*.

6.9.2. Doctors

Undeniably, the most important player in decision-making is the doctor. This is shown in the interviews for their expertise in handling DSD cases. Patient's agreement or refusal of the treatment is basically a response to the clinical recommendation initiated by the doctors. Even though patients bear the consequences, be they positive or negative, it reflects the professionalism of the career. For example, the religious group known as Jehovah's Witnesses takes a stance on the refusal of blood transfusions based on the tenet of the religion. For the attending healthcare providers, it is their duty to manage the patients to reduce the risk of blood loss and the risk of the subsequent need of a blood transfusion. The art of managing patients from the various religious and cultural background is crucially required to carry out their responsibilities and to ensure the highest level of patients' quality of life.

The doctors, who hold complete executive capacity, should be respected for their expertise and knowledge regardless of their religion in order to exercise their duties. The Qurʾān highlights this important message in *Sūrah al-Anbiyāʾ*: "If you realise this not, ask of those who possess the Message."[651] This verse is repeated twice in the Qurʾān and was initially revealed in response to the questions about the creed of Islam.[652] Yet, an Islamic legal maxim notes that 'a lesson is to be considered on its general term, not on its specific reason' (*al-ʿibrah bi ʿumūm al-lafẓ laysa bi khuṣūṣ al-sabab*). Clearly, the spirit of this verse indicates the importance of referring to the experts in their own field.[653] Therefore, a doctor's recommendation of medical intervention should not be ignored.

[651] ʿAbdullah Yūsuf ʿAlī, *The Holy Qur´an Text, Translation and Commentary*. *Sūrah al-Anbiyāʾ* (The Prophets), 21: 7.

[652] According to most commentators, 'those who possess the Message' refers to a group of religious scholars such as people of Torah and Gospel, Islamic scholars or the believers among people of the Book. See more in Al-Suyūṭī, Jalāl al-Dīn ʿAbd al-Raḥman Ibn Abū Bakr, *Al-Durr Al-Manthūr* (Beirut: Dār al-Fikr, 2010).

[653] Abū ʿAbd Allah Al-Qurṭubī, *Al-Jāmiʿ Li Aḥkām Al-Qurʾān (The Compiler for Qurʾanic Rulings)*, ed. by Aḥmad Al-Bardūnī and Ibrāhīm Aṭfīsh, 2nd edn, (Cairo: Dār al-Kutub al-Miṣriyyah, 1964) vol. 2, p. 212.

The experts who possess the knowledge should be a qualified person, authorised by the state and competent enough to carry out the duties. The Prophet once mentioned: "He who undertakes the treatment of others, without preparing himself and causes loss of life or damage is held liable."[654] Ibn Qayyim (d. 748 AH/1347AH) a Ḥanbalī jurist, elaborates on the liability of the doctor according to the capability in providing necessary treatment.[655] Ibn Qayyim adds the liability is held if the treatment conducted without the consent of the patient.

In addition, doctors should also assist to enhance the capacity of the patients in dealing with the recommendations. Barriers like poor hearing and eyesight, jargon words, different language or dialect, should be removed through appropriate mechanisms such as audio and visual devices, infographic information, translator etc. Ample time and space should also be provided, in non-emergency cases, to ensure the patients have acquired the information and understand the situation leading towards making an informed decision.

6.9.3. Parents

As DSD is one of paediatrics' branches, parental roles over minor patients are vital in this context. Parents or guardians with complete executive capacity are expected to exercise their responsibilities in order to ensure the children's imperfect receptive capacity is fulfilled. The voice of the parents is as important as the child's life in emergency cases. Their opinions, on behalf of the children, in other cases are also of high importance for the doctors to pursue the treatment. Their interest to see the affected ones live their lives as others is always the main objective. Guardianship of a person applies to safeguarding the needs of the minor patients to restore their quality of health and ensure a better environment for their upbringing.

[654] Abū Dāud, Abū Sulayman Ibn al-Ashʿath, *Sunan Abī Dāud*, ed. by ʿAbd al-Ḥamīd, Muḥammad Maḥy al-Dīn (Beirut: Al-Maktabah Al-ʿAṣriyyah, n.d.). vol. 4, *Bāb fī man taṭabbaba bi ghayr ʿilm faʾaʿnt* (Chapter Who Medically Treats a Person without Knowledge, He is Held Liability), p. 195.

[655] Ibn al-Qayyim al-Jawziyyah, Muḥammad Ibn Abī Bakr, *Zād Al-Maʿād Fī Hadyi Khayr Al-ʿIbād (Provisions for the Hereafter in Guiding the Best Worshipper)* (Beirut: Muʾassasah al-Risālah, 1994) vol. 4, p. 130.

Limited knowledge and awareness, cultural traditions, strict adherence to religion and social expectations are identified as non-medical contributors to decision making. Unsurprisingly, one of the respondents conveyed that parents are responsible for minor patients, but their decision is not absolute. Therefore, knowledge is deemed to be the main element in providing the informed decision. Besides, extensive knowledge will secure an unwavering decision, despite unwanted pressure from other family members and society.

On the other hand, in Asian countries, the roles of parents or families are extended even to the adult patient's decision. The attachment of a person to the family is very high, especially when that relates to their entire life. In this situation, personal autonomy decreases, or, in other words, the personal autonomy is transferred to the consultation with the family. This justifies the importance of parents and families as the main actors in the decision-making process.

The concern of infringement of the child's rights is usually raised if there is an occurrence of gender misassignment or adverse effect of surgical treatment. However, the care and protection of children is religiously accepted and legally bonded. For example, in Malaysia it has been adopted into *Paediatric Protocol for Malaysian Hospitals* in the general care of DSD as below:

> "Open communication with patients and family is essential, and participation in decision making is encouraged. Patients and family concerns (e.g., social and culture) should be respected and addressed."[656]

Therefore, the authority of the parents over the minor patients is unquestionable. The infringement of a child's rights could not possibly arise if the management of consultation and treatment were conducted as recommended in the Chapter 4 and Chapter 5 on gender assignment and the treatment.

6.9.4. Religious Leaders

Another party that is increasingly referred to, especially in the Muslim context, is religious leaders. Religious leaders in such groups might be referred to as imams,

[656] Hussain Imam Muhammad Ismail, Ng Hoong Phak and Terrence Thomas, *Paediatric Protocols for Malaysian Hospitals*, 3rd edn (Putrajaya: Kementerian Kesihatan Malaysia, 2013).

Muslim chaplaincy, Muslim scholars, religious officers or Muftis. In minor Muslim community contexts, for instance in the United Kingdom, where governmental institution for this religious group is unavailable, the roles of Muslim chaplaincy and their cooperation and engagement with public sector is much more appreciated. Their roles are expanded from private sphere to public institutions like prisons, airports, educational institutions, courts, shopping centres and most importantly in hospitals. In the healthcare settings, their roles are beyond simply advising on basic religious needs, which is largely an extension of mosque-based imam's roles.[657] It is not only confined to what they can provide but it becomes incumbent to all NHS employee to show respect for patients' religious belief and patients' requirement to seek support from religious experts.[658]

In dealing with cases like DSD, Zuhayr Aḥmad al-Sibāʿī and Muḥammad ʿAlī al-Barr opine that religious scholars could deal with the patients in terms of juridical rulings, based on the medical recommendations, after gender assignment has been made by the doctor.[659] However, based on the interviews, their crucial role goes beyond that of merely preaching, i.e., post-medical intervention. Conversely, the Islamic scholars proposed for their involvement during the decision-making process and their opinions are welcomed by the medical practitioners. It is consistent with an analytical study on fatwas written by the researcher related to the issue of gender ambiguity. The study shows that those fatwas are being referred to by the medical practitioners in handling cases of gender assignment and its treatment, in which it is part and parcel of decision-making process.[660]

Other studies conducted by A. R. Gatrad and A. Syeikh, as well as Ani Amelia Zainuddin and Zaleha Abdullah Mahdy, propose for the participation of religious scholars in a Multidisciplinary Team (MDT) of managing patients with DSD.[661] An

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[658] Sophie Gilliat-Ray, Mansur Ali and Stephen Pattison, p. 7.

[659] Zuhayr Aḥmad Al-Sibāʿī, Muḥammad ʿAli Al-Barr, *Al-Ṭabīb Adabuh wa Fiqhuh (Ethics of Physicians and Jurisprudence)* (Damascus: Dār al-Qalam, 1993).

[660] Taqwa Zabidi, 'Analytical Review of Contemporary Fatwas in Resolving Biomedical Issues Over Gender Ambiguity', *Journal of Religion and Health,* (2018), pp. 1-15.

[661] A. R. Gatrad and A. Sheikh, 'Medical Ethics and Islam: Principles and Practice', *Arch Dis Child,* 84 (2001), p. 72-75.; Ani Amelia Zainuddin and Zaleha Abdullah Mahdy, 'The Islamic Perspectives of Gender-

imam who is well informed on the matter of DSD may promote a better way of treatment. Instead, a less well-informed imam may influence the patients' view of the treatment adversely. His unwise opinion may also have a negative impact the life of the patient thereafter. Hence, Muslim scholars should equip themselves with current and empirical knowledge of DSD in order to enhance their capability in good decision-making. They should more importantly be acquainted with the cause of rulings known as *taḥqīq al-manāṭ* in the principles of Islamic jurisprudence and seek its consistency in medical perspectives.[662] Further study will be explored in the next chapter on to what extent they can exercise their duties and what are the challenges they should face in handling DSD cases.

This chapter has shown that the roles of patients, doctors, parents and religious leaders are important at the table of discussion. Their competency in exercising their duties should not be ignored. The most important factor of their role, ultimately, is to equip themselves with knowledge. Throughout the process, exchange of knowledge by all parties will enrich the discussion. Understanding the circumstances from different backgrounds of expertise will ensure a more contented situation despite the complexity of the condition.

6.10. Consultation (*Shūrā*) as a Platform of Exercising Autonomy

The relationship of all actors can be observed through several approaches of medical decision making. The type of relationship shifts from one pattern to another, although the former maybe still being practiced due to individual behaviour, circumstances, time consultation constraint, physicians' workload and other issues. Among them, the most practical approach is identified to cater for the need of exercising consultative autonomy, by taking into account the participants in the decision-making process and its practicality for the management of patients with DSD.

Related Issues in the Management of Patients with Disorders of Sex Development', *Archives of Sexual Behavior*, (21 April 2016), pp. 1-8.

[662] Sayed S. Haneef and Mahmood Zuhdi Abdul Majid, 'Medical Management of Infant Intersex: The Juridico-Ethical Dilemma of Contemporary Islamic Legal Response', *Zygon: Journal of Religion & Science*, 50 (December 2015), pp. 809-829.

As Islamic law underlies that every competent *mukallaf* is responsible to discharge their legal duties, the researcher argue that exercising autonomy is not limited to the patient only. Respect for the person that was pronounced in the Belmont Report, should be extended to all actors in this process. Doctors and patients have their own autonomous sphere within their own capacities and capabilities in contributing towards the betterment of the treatment. In addition, the roles of parents and Muslims scholars should be acknowledged within their own rights.

The platform to exercise equal power of autonomy is through consultation. In Islam, consultation is a recognised medium because it has been mentioned in a number of verses of the Qurʾān, and in examples of the Prophets' action and guidance on life management.[663] The system and rules to be used are left silent in the Qurʾān, hence gives a flexible and adaptable context for varied and changing situation.

In this sense, consultative autonomy matters. The autonomous power relies on a group of people who would like to achieve the same goals and objectives. Al-Raysūnī, a contemporary scholar highlights that consultation will only succeed in the atmosphere of freedom of conscience, freedom of thought and freedom of speech.[664] Everybody must be free to express their values, convictions, thought and knowledge. This platform will enable the process of exchanging information and breaking down any barriers to understanding each other. Coercion and interference will be non-existent in the sense that everybody is consulting with each other to achieve a unanimous decision.

Hence, the four elements of; i) self-determination with optimum capability and competency, ii) free from coercion and interference, iii) free from limitations such as inadequate understanding, and iv) guided and governed by the objectives of sharīʿah must be acknowledged in the process of consultation. Therefore, the researcher strongly opines that consultation is a platform for exercising autonomy. The

[663] One of the most quoted verses is in *Sūrah Āli ʿImrān* (3: 159). The Qurʾān, as its translation, mentions: "…so pass over (their faults), and ask for (God's) forgiveness for them; and consult them in affairs (of moment)"

[664] Ahmad Al-Raysūnī, *Al-Shūrā the Qurʾanic Principle of Consultation,* trans. by Nancy Roberts (USA: International Institute of Islamic Thought, 2012) p. 21. Al-Raysūnī is a Moroccan scholar of Sunni school of thought. His contribution is renowned in developing the theory of *maqāṣid al-sharīʿah* and its application. He is currently the President of International Union of Muslim Scholars.

autonomous power reverts to its original practice of a government, which is consultative in nature.

6.11. Decision Making Model for Disorders of Sex Development (DSD)

Based on the discussion of autonomy and competency of the actors in the decision-making process, the shared decision-making model is the best fit for managing patients with DSD. There is plenty of literature that advocates shared decision making for DSD since the Chicago Consensus was made.[665] Multidisciplinary Team (MDT) was proposed to cater for problem at hospitals. A MDT involves the referring doctor, other related doctors from various sub-specialization of paediatrics, the patient and the parents. In other words, it takes the concept ***shūrā*** (consultation) to maximize the impact and minimize the risk. ***Shūrā*** "requires a system, or a detailed set of rules, which has been left silent by Islamic law."[666] Hence, the standard protocol that has been established as in the United Kingdom and Malaysia should be referred in implementing the procedure of decision-making process.[667]

In Malaysia, a Multidisciplinary Team was established at the National University Malaysia in 2014. Since its inception, a number of cases have been managed, regardless the religion of the patients. It is called as Multidisciplinary Team of Management of Patients with Disorders of Sex Development. In Indonesia, awareness about the management of DSD was started as early as 1989 in collaboration with Dr. Kariadi Hospital and the Faculty of Medicine of the Diponegoro University in

[665] Kathleen Graziano and Mary E. Fallat, 'Using Shared Decision-Making Tools to Improve Care for Patients with Disorders of Sex Development', *Advances in Pediatrics*, 63 (2016), 473-480; I. A. Hughes, 'Consequences of the Chicago DSD Consensus: A Personal Perspective', *Hormone and Metabolic Research*, 47 (2015), 394-400; Mary Elizabeth Moran and Katrina Karkazis, 'Developing a Multidisciplinary Team for Disorders of Sex Development: Planning, Implementation, and Operation Tools for Care Providers', *Advances in Urology*, 2012 (2012), 1-12; L. A. Siminoff and D. E. Sandberg, 'Promoting Shared Decision Making in Disorders of Sex Development (DSD): Decision Aids and Support Tools', *Hormone and Metabolic Research*, 47 (2015), 335-339.

[666] Ahmad Al-Raysūnī, *Al-Shūrā the Qur'anic Principle of Consultation,* p. 42.

[667] S. Faisal Ahmed and others, 'Society for Endocrinology UK Guidance on the Initial Evaluation of an Infant and Adolescent Suspected with Disorders of Sex Development (Revised 2015)', *Clinical Endocrinology*, 0 (2015), 1-18; Caroline E. Brain and others, 'Holistic Management of DSD', *Best Practice & Research Clinical Endocrinology & Metabolism*, 24 (2010), 335-354; Hussain Imam Muhammad Ismail, Ng Hoong Phak and Terrence Thomas, p. 269.

Semarang, Central Java. The team is known as *Tim Penyesuaian Kelamin* (the Sexual Adjustment Team).[668]

The components of a Multidisciplinary Team may vary from one hospital to another depending on the availability of the specialists. At least, the typical members of the team should consist of: the referring physician (obstetrician or paediatrician), a paediatric endocrinologist, a paediatric surgeon (urologist or gynaecologist), a geneticist and either a psychiatrist, psychologist or psychoendocrinologist.[669] At the Great Ormond Street Hospital for Children (GOSH), the United Kingdom, a biochemist is also included within the MDT.[670] Apart from the core member of the team, I.A. Hughes notes that the participation of other important parties could be nurses, social workers, ethicists and religious leaders.[671] The Sexual Adjustment Team of Dr. Kariadi Hospital, Indonesia consists of those core members plus a plastic surgeon, anaesthesiologist, medico-legal professional, religious expert and social medical staff.[672]

The information gathered by the doctors, the patients and the parents may be overwhelming and possibly conflicting. In order to manage this information properly and to consider the most important aspects, Graziano and Fallat propose decision-making tools which are divided into five sections.[673] Firstly, basic information of the patients or the parents' view of the diagnosis, and the culture and values that need to be addressed. The second section is for nomenclature or preferred terms that the family like to use. The third section is on the list of short term and long term topics. The fourth section is on the questions that need to be addressed by the providers and lastly, a list of treatment options including non-surgical options. Sometimes, the

[668] Annastasia Ediati, p. 19.

[669] Suzanne J. Kessler, 'The Medical Construction of Gender: Case Management of Intersexed Infants', *Signs*, 16 (1990), 3-26, p. 11; Further reading on the specific roles of those medical team members can be referred to Caroline E. Brain and others, 335-354.

[670] Caroline E. Brain and others, p. 336.

[671] I. A. Hughes, pp. 394-400.

[672] Nurin Aisyiyah Listyasari and others, 'Multidisciplinary Management for Disorders of Sex Development, A Prototype for Developing Country', *Journal of Biomedicine and Translational Research*, 1 (2017), 17-22, p. 18.

[673] Kathleen Graziano and Mary E. Fallat, 'Using Shared Decision-Making Tools to Improve Care for Patients with Disorders of Sex Development', p. 477.

patients and the parents do not know what to ask. Thus listing the points is empowering.

While shared decision making is proposed within Multidisciplinary Team in managing patients with DSD, there are challenges with regard to the commitment of the patients or the parents/guardians. In a developing country, geographical distance to a referral hospital with less financial support and poor transportation could add another predicament to a successful negotiation and treatment planning. A long distance for a medical follow-up requires leave of absence from working and leaving other family members at home. This is the issue in Indonesia.[674] A preliminary survey conducted in the main tertiary centre in Malaysia indicates that long distance and a high cost of travel could be the external factors that cause unsuccessful discussions.[675]

The case of AA forwarded to the Department of Islamic Development Malaysia shows that a 46,XX baby born in a rural town was diagnosed with salt-wasting CAH.[676] The baby was assigned as a girl based on medical protocol and underwent irreversible surgery at the age of 5 years. At the age of 7 years, she insisted she was a boy and later experienced male puberty development. Based on the medical record, she had long-standing medical non-compliance history due to living far from the tertiary hospital she needed to attend for treatment and to get the required medicine.[677] After 20 years struggling with her social life, she requested for sex reassignment. This example shows that although the decision making took place in a partnership setting with the Multidisciplinary Team, the external factor of geographical distance may cause difficulty to ensure smooth and effective discussion and follow-up treatments, hence poor medication compliance.

[674] Nurin Aisyiyah Listyasari and others, 'Multidisciplinary Management for Disorders of Sex Development, A Prototype for Developing Country', p. 18; Ani Amelia Zainuddin and others, 'Research on Quality of Life in Female Patients with Congenital Adrenal Hyperplasia and Issues in Developing Nations', *Journal of Pediatric and Adolescent Gynecology*, 26 (December 2013), 296-304, p. 300.

[675] Ani Amelia Zainuddin and others, 'Research on Quality of Life in Female Patients with Congenital Adrenal Hyperplasia and Issues in Developing Nations', p. 300.

[676] Taqwa Zabidi, Ani Amelia Zainuddin and Bettina E. Schmidt, 'An Analysis of Islamic Biomedical Ethics in Managing Patients with Disorder of Sex Development: An Experience in Malaysia', *Medicine and Law*, 35 (2016), 345-364, p. 346.

[677] Taqwa Zabidi, Ani Amelia Zainuddin and Bettina E. Schmidt, 'An Analysis of Islamic Biomedical Ethics in Managing Patients with Disorders of Sex Development: An Experience in Malaysia', p. 347.

6.12. Conclusion

The whole discussion in this chapter is pertaining to the actors of the decision-making process. In Islamic jurisprudence, the person whose juridical rulings subjected to them is known as *al-maḥkūm ʿalayh*. Both medical and Islamic perspectives point out that the essential element for the actors involved in the decision-making process is competency. Biomedical ethics views competency as the vehicle to be autonomous agents. In history, it was the rise of socio-development that triggered the struggle for acquiring the rights of autonomy especially among the patients. Therefore, the focus has been given to the needs of the patients and the importance of respecting their decision. As time passed and ideas changed, the pattern of patient-doctor relationship demands for balance role of both parties and other related actors. It is vital especially in managing a complex condition like DSD.

In contrast, Islamic ethics focuses on competency in performing of the duties. It implies that everyone who is attributed to the management of patients with DSD should carry out the duties within their own sphere. Explication of capacity also underlies the requirements of guardianship over children and another person's with imperfect or deficient capacity. As every related party, who is *mukallaf* (capable) is subject to perform their duties, those responsibilities are expected to be performed even in the decision-making process. This concept is in harmony with the commandment of Allah in exercising consultation or ***shūrā***.

However, different backgrounds come to the same end. Both Islamic and medical perspectives call for mutual agreement in the decision-making process. Consultative autonomy could be applied through ***shūrā*** or what is termed in the medical setting as the shared decision-making model. The roles of all actors in this process are clearly explained, except for religious leaders, as crucial for a successful outcome. The next chapter will explore the roles of religious authority in comparison of three regional countries, namely Malaysia, Singapore and Indonesia.

7. ROLES OF RELIGIOUS AUTHORITIES IN THREE REGIONAL COUNTRIES

7.1. Overview

This chapter is an extension of the previous chapter on decision making process by responding to the third objective of this research. While most literature considers patients, doctors and families as the actors in decision making, our interviews conducted found that the roles of religious scholars are appreciated in managing patients with DSD. Therefore, this chapter will analyse the extent to which the role of religious leaders is important in Multi-Disciplinary Team (MDT) in managing DSD cases. For better analyses, comparison is made between three regional countries, namely Malaysia, Singapore and Indonesia. These countries have been chosen due to the fact that they share common values especially in terms of relying on Sunni approach of Islamic teachings and practices similar customs among Malays.

This chapter begins with the background of the issue related to the roles of religious leaders. It is followed by basic understanding of their expected roles according to Islamic perspectives. The discussion will then focus on the comparison between the three countries. This chapter provides general observations of Islam and its administration within those countries and how Islamic bioethics is given consideration by the governments. Based on interviews with representatives of religious leaders in all countries, their roles will be presented in the following subtopic. Considering the Islamic administration and governance, this research identifies several challenges for the involvement of religious leaders in the MDT as presented at the end of this chapter.

7.2. Basic Understanding on the Roles of Authorities from the Islamic Perspective on Dealing with Cases of Disorders of Sex Development

The proliferation of a range of complex issues related to DSD has led to ethical dilemmas among physicians, patients and society at large.[678] For Muslims religion has become a set of tools in resolving issues related to biomedical ethics. It appears that

[678] A. R. Gatrad and A. Sheikh, 'Medical Ethics and Islam: Principles and Practice', *Arch Dis Child,* 84 (2001), p. 73.

the role of imams, Islamic religious leaders or even greater powers of Islamic authority in major Muslim countries, are clearly essential in shaping patients' notions of health, doctor-patient relationships and healthcare-seeking attitudes. The scenario seems similar to the management of patients with DSDs in the medical environment. Multidisciplinary Teams (MDT) for managing patients with DSD consist of numbers of medical experts as the core members. On top of that, religious leaders are considered as the supporting group along with others such as nurses, social workers and ethicists.

In Muslim communities, religious leaders could be those who have well-versed knowledge in Islamic teachings at several levels. They may be within the communities, in certain organizations or even at the national level like muftis or administrators of Islamic affairs. The scenario of having religious leaders as one of the actors in the decision-making process has been discussed in subtopics 6.8 and 6.9 in Chapter 6. For the purpose of this research, we have already seen that MDT have been established in Malaysia and Indonesia at the authoritative levels. Therefore, the roles of Islamic authorities will be analysed in this chapter, by comparing their roles in three regional countries i.e. Malaysia, Singapore and Indonesia.

In an Islamic-accentuated community, religion is an integral part of one's belief system that guards life, at least for some people, if not all. For example, some Muslim patients hesitate to consult with physicians, pertaining to gender ambiguity, but rather seek the local imams' opinions as argued by Sabah Alvi, a Paediatric Consultant and Adolescent Endocrinologist whom the researcher met in the 5th International Symposium of DSD at Belgium in 2015. [679] She caters a number of Muslim patients at the hospital. Most of them rely on imams' opinions more than the clinicians. Perhaps, it is because this condition is closely related to the prohibition of altering Allah's creation, including gender. It seems that seeking the imam's views is more appeasing and convincing when it comes to medical matters that are closely linked to religious belief. In other instance, Ediati also highlights that the management of individuals with

[679] Sabah Alvi is a Consultant Paediatric and Adolescent Endocrinologist at the Leeds Teaching Hospital NHS Trust whom the researcher met during the I-DSD International Conference 2015, in Belgium.

DSDs is often in stark contrast to medical outcomes when religious belief dominates the decision-making process.[680]

It is important to not only focus on the medical and psychological aspects but to look into religious roles in such communities.[681] Meyer-Bahlburg points out that 'the clinician's role is not to superimpose his/her cultural values on those of others, but to come to a decision that likely minimizes potential harm to the patient in his/her cultural environment.'[682] I.A. Hughes, an Emeritus Professor of Paediatrics at the University of Cambridge, states his personal perspective on DSDs after 10 years of implementation that 'religious leaders, like any other ethicists, social workers and the local community may be involved as necessary, although their involvement is not as core members of the Multidisciplinary Team (MDT)'.[683] They are essential in providing guidance with regard to an individual's belief as a continuous support over time.[684] Ani Amelia Zainuddin stresses the need for the inclusion of religious authorities in the MDT, because many decisions pertaining to clinical management 'affect the religious aspects of life, and thus the outcomes of individual patients, their families and the community'.[685]

Let us take a look at two verses of the Qurʾān pertaining to the status of those with authority.

> "O ye who believe! Obey God, and obey the Messenger and those charged with authority among you."[686]

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[680] Annastasia Ediati, 'Disorders of Sex Development in Indonesia: The Course of Psychological Development in Late Identified Patients' (PhD, Diponegoro University, Semarang, Indonesia, 2014), p. 381.

[681] Nasir A. M. Al-Jurayyan, 'Disorders of Sex Development: Diagnostic Approaches and Management Options - an Islamic Perspective', *Malaysian Journal of Medical Science*, 18 (Jul - Sep 2011), pp. 4-12; Nabil M. Dessouky, 'Gender Assignment for Children with Intersex Problems: An Egyptian Perspective', *Egyptian Journal of Surgery,* 20 (April 2001), pp. 499-515; Garry L. Warne and Jamal Raza, 'Disorder of Sex Development (DSDs), Their Presentation and Management in Different Cultures', *Rev Endorc Metab Discord,* 9 (2008), pp. 227-236.

[682] Heino F. L. Meyer-Bahlburg, 'Gender Assignment in Intersexuality', *Journal of Psychology & Human Sexuality*, 10 (1998), 1-21.

[683] I. A. Hughes, 'Consequences of the Chicago DSD Consensus: A Personal Perspective', *Hormone and Metabolic Research*, 47 (2015), p. 396.

[684] Caroline E. Brain and others, 'Holistic Management of DSD', *Best Practice & Research Clinical Endocrinology & Metabolism,* 24 (2010), p. 347.

[685] Ani Amelia Zainuddin and Zaleha Abdullah Mahdy, 'The Islamic Perspectives of Gender-Related Issues in the Management of Patients with Disorders of Sex Development', *Archives of Sexual Behavior*, (21 April 2016), p. 7.

[686] Translation of the Qurʾān in ʿAbdullah Yūsufʿ Alī, *The Holy Qur´an Text, Translation and Commentary*, New Revised edn (Brentwood: Amana Corporation, 1989). Sūrah al-Nisāʾ (The Women), 4: 59.

> "When there comes to them some matter touching (public) safety or fear, they divulge it. If they had only referred it to the Messenger or to those charged with authority among them, then the ones who can draw correct conclusions about it would have known about it."[687]

These verses indicate, firstly, the high rank of authority, after God and the Prophet Muḥammad. Secondly, the importance of the roles of the authorities in the public sphere and that they are to be obeyed by the citizens. Scholars debate on who is the *ʾulu al-amr* (to use the Qurʾanic term of 'those charged with authority'). Literally, *ʾulu* refers to 'those of' or, 'those who' and *al-amr* refers to a state of either 'to order an action' or 'to prohibit an act'.[688] Abū Isḥāq (d. 476 AH/1083 CE), a Shāfiʿī scholar defines it as the Companions of the Prophet Muḥammad.[689] Al-Māwardī (d. 450 AH/1058 CE) cites two opinions in his book *Al-Aḥkām al-Sulṭāniyyah* that *ʾulu al-amr* refers to the leaders as mentioned by Ibn ʿAbbās (d. 68 AH/687 CE), the Companion.

Secondly it refers to the views of Jābir Ibn ʿAbdullah (d. 78 AH/697 CE), al-Ḥasan al-Baṣrī (d. 110 AH/ 728 CE) and ʿAṭāʾ Ibn al-Sāʾib (d. 136 AH/753 CE) that those with the authority are the Islamic scholars.[690] Al-Qurṭubī (d. 671 AH/ 1273 CE) defines *ʾulu al-amr* as those knowledgeable and experts, or the leaders who have been given the power to exercise it in such a manner.[691] In fact, there is no specific definition from the Qurʾān and Ḥadīth on who is eligible to be identified as *ʾulu al-amr*. At least, verse 83 from *Sūrah al-Nisāʾ* guides us that this group of people charged with authority are eligible for being obeyed by the *ummah* (community), and that the temporal power they hold is upheld by the practice of consultation (*shūrā*).

While speaking on authority and obedience within the Islamic context, Muslims are obliged to abide by the sharīʿah law and the people in power are the entity to regulate

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[687] Translation of the Qurʾān of *Sūrah al-Nisāʾ* (The Women), 4: 83, translated by the researcher based on the commentaries of the Qurʾān.

[688] Translation is provided by the researcher.

[689] Abū Isḥāq cited Ibn Manzur, vol. 11, p. 27.

[690] ʿAlī Ibn Muḥammad Al-Māwardī, *Al-Aḥkām Al-Sulṭāniyyah (the Ordinances of Government)*, ed. by Aḥmad Jād (Cairo: Dār al-Ḥadīth, n.d.), pp. 85-86.

[691] Abū ʿAbd Allah Al-Qurṭubī, *Al-Jāmiʿ Li Aḥkām Al-Qurʾān (the Compiler for Qurʾanic Rulings)*, ed. by Aḥmad Al-Bardūnī and Ibrāhīm Aṭfīsh, 2nd edn, (Cairo: Dār al-Kutub al-Miṣriyyah, 1964), p. 291.

and exercise the law. The obedience and submission are none but to only God.[692] The act of obedience towards the Prophet as the Messenger of God is also ordered as well as towards people who are trusted to and capable of bringing the nation towards the goal of achieving benefits and avoiding harms as prescribed by the Divine revelations according to Sunni scholars. Hissien Faradj argues that the Companions are both leaders and scholars that makes them eligible them to be identified as *ʾulu al-amr* as mentioned by Abū Isḥāq. However, due to geopolitical change ever since, there has been a separation of power between the leaders (*ʾumarāʾ*) and the scholars (*ʿulamāʾ*).[693] Aḥmad Jād cites Muḥammad Shaltūt's (d. 1963) view that in the contemporary political era, the authorities are those who are well-versed in the nations' interests in various fields and have expertise in such areas as defence, finance, international affairs and others.[694] Hence, they are the leaders of the nation, whose consensus and agreement must be conformed with.[695]

The use of this state power is closely related with the principle of *shūrā* (consultation) as discussed in the previous chapter. Variations of examples in the Qurʾān on how consultation should take place open up numerous techniques for its implementation.[696] In the case of highly specialized field like medical cases, only those who are highly qualified and who have specific expertise should become involved. Consultation entails exchanging of information and will later be seen to assist in the process of assessment, planning and decision making in cases of DSD. Once sufficient experts are engaged, there is no need to broaden the consultation.

The consultative approach is seen in current effective governance practice, also in Islamic affairs. The term *ʾulu al-amr* in the contexts of Malaysia, Singapore and Indonesia also denote the roles of the responsible organizations for Islamic affairs and

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[692] This refers to verse 56 of *Sūrah al-Zāriyāt* (The Winnowing Winds): "I have only created Jinns and men that they may serve Me."

[693] Hisseine Faradj, 'Ulu Al-Amr & Authority: The Central Pillars of Sunni Political Thought' (Doctor of Philosophy, City University of New York, 2014), p. 46 [Online] Available at <https://academicworks.cuny.edu/gc_etds/347> [accessed 26 October 2019].

[694] Muḥammad Shaltūt was an Egyptian religious scholar and Grand Imam of Al-Azhar. He endeavoured to reform al-Azhar and bring back this institution as an active participant in Egypt's educational, political and cultural values by employing sharīʿah as a source of modern legislation.

[695] Muḥammad Shaltūt cited in ʿAlī Ibn Muḥammad Al-Māwardī, *Al-Aḥkām al-Sulṭāniyyah*, p. 85.

[696] The Qurʾanic examples of consultation involve matters in managing breastfeeding (*Sūrah al-Baqarah*, 2: 233), marital discord (*Sūrah al-Nisāʾ*, 4: 128), national safety (*Sūrah al-Naml*, 27: 32) and ritual sacrifice of Abraham's son (*Sūrah al-Ṣāffāt,* 37: 102).

the Islamic scholars. The responsible organizations are depicted through the function of related Ministries or other departments or divisions under their jurisdictions. Whilst, the Islamic scholars could be varied in terms of their roles either as imams, teachers, preachers or muftis (jurist-consults). For the purpose of this research, focus is given to the latter group, muftis, as the highest level of scholars whom the citizen refer to most. Their expertise is acknowledged at the national level. A mufti, according to al-Nawāwī, is defined as:

a. a reliable Muslim with high moral values, safe from immorality and dishonour; and
b. Has a practical technique for deducing new rulings from the proofs of injunctions (*adillah al-aḥkām*) including the Qurʾān, Ḥadīth, ʾ*ijmāʿ* (consensus) and *qiyās* (analogical reasoning).[697]

Currently, the position of the jurist-consult is beyond a mere individual opinion. It has become a referral institution for Muslims in resolving contemporary issues.[698] The institution of Fatwa Committee is seen as a manifestation of collective *ijtihād* (legal independent reasoning) where more experts are involved at a table of discussion.[699]

The idea of collective *ijtihād* is proposed by Rashīd Riḍā (d. 1935) and he relates this notion to *al-ʾijmāʿ'* (consensus).[700] His idea was expanded by Sanhuri and Shalabi to make the institution of *ijtihād* as equivalent to the classical *al-ʾijmāʿ*.[701] However, Aznan Hasan, a contemporary scholar in Islamic Law, claims that there are a few characteristics of classical ʾ*ijmāʿ* that are difficult to accomplish by contemporary collective *ijtihād*. Firstly, it pertains to the determinants of *mujtahidūn* (plural *mujtahid*: one who exercises independent reasoning (*ijtihād*) in the interpretation of Islamic law) and how are they to be gathered from all over the world. Secondly, currently there are Fatwa Committees all around the world. It is impossible to relinquish their status quo in order to establish only one body of *mujtahidūn*. Thirdly is with regard to the infallibility

[697] Yahyā Sharaf Al-Nawāwī, *Adāb Al-Fatwā Wa Al-Muftī Wa Al-Mustaftī (Ethics of Fatwa, Jurist-Consult and Interlocutor)* (Damascus: Dār al-Fikr, 1408H).

[698] Muhammad Ifzal Mehmood, 'Fatwa in Islamic Law, Institutional Comparison of Fatwa in Malaysia and Pakistan: The Relevance of Malaysian Fatwa Model for Legal System of Pakistan', *Arts and Social Sciences Journal,* 6 (2015), pp. 1-3.

[699] See subtopic 2.3.1.3, Chapter 2, for a brief explanation on *ijtihād.*

[700] Muḥammad Rashīd Riḍā, *Al-Khilāfah (the Caliphate)* (Cairo: Al-Zahrāʾ li al-Aʿlām al-ʿArabiy, n.d.), p. 113.

[701] Sanhuri and Shalabi cited in Aznan Hasan, 'An Introduction to Collective Ijtihad (Ijtihad Jama'i): Concept and Applications', *The American Journal of Islamic Social Sciences,* 20 (2003), p. 33.

of the institution to reach the status of irrevocable, unopposed and the fatwas are not reinterpreted by the later generation because one of the characteristics of *al-ʾijmāʿ* is that the decision made in particular period of time cannot be altered by people in the later period.[702]

Therefore, he argues that collective *ijtihād* (legal independent reasoning) should be ranked second after the classical *ʾijmāʿ* (consensus) and higher than individual *ijtihād*. The collective *ijtihād* is essential for Islam's continuity and survival in the modern world. The consultative committees should consist of jurists that reach to the rank of *ijtihād,* jurists who are not yet *mujtahidūn*, and researchers in Islamic studies. However, in a practical sense, it is very challenging to ensure the involvement of a *mujtahid* in such committees. Nonetheless, the involvement of jurists who are knowledgeable in applying the principles of Islamic jurisprudence is essential. The committee should also comprise of professionals in other required expertise such as medical practitioners for discussing the medical issues. Although participation of other professionals does not hold the same authority in Islamic law, any agreement with the government on the status of its authority could enhance its capability and reliability.[703]

Coming back to the question of the roles of Islamic authorities in managing patients with DSD, a research has been conducted to observe juristic councils' attitudes towards this opinion. Surprisingly, none of them made suggestions for the involvement of Muslim scholars in the Multidisciplinary Team (MDT).[704] Whether the existence of a MDT is realized or not, most of the available fatwas alternatively emphasize the importance of seeking consultation with the physicians in order to ensure the appropriate signs of the dominant sex and the ensuing treatment. For instance, the juristic council of United Arab Emirates highlights the significance of a specialized medical team whose decision will result in a particular individual behaviour and consequent Islamic juridical rulings.[705]

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[702] Aznan Hasan, p. 37.

[703] Aznan Hasan, pp. 37-38.

[704] Taqwa Zabidi, 'Analytical Review of Contemporary Fatwas in Resolving Biomedical Issues Over Gender Ambiguity', *Journal of Religion and Health*, (2018), pp. 1-15.

[705] General Authority of Islamic Affairs and Endowment, *Min Aḥkām Al-Khunthā (Among the Rulings for Hermaphrodites)*, (Federal Government United Arab Emirates, 9 May 2016) <*http://www.awqaf.gov.ae/Fatwa.aspx?SectionID=9&RefID=2571*>, [accessed 10 May 2016].

Based on the interviews conducted, the scenario of having a religious leader as one of the actors in the decision making process in Malaysia, Singapore and Indonesia has been discussed in subtopic 6.8, Chapter 6. In order to determine the need for their involvement in the MDT, the roles of religious authorities are examined with a comparison of three countries in the same geographical region: Malaysia, Singapore and Indonesia as the following.

7.3. Islam and Its Administration in Malaysia, Singapore and Indonesia

In Malaysia, Islam is largely practised by Malays, the major component of Malaysian ethnics. Due to political movements, Malays also found permanent settlement in Singapore and are actually predominant in Indonesia.[706] They share a lingua franca and important elements of common values and cultures. Muslims in these three countries mainly follow the Shāfiʿī school of Sunni jurisprudence. The distinctive features are that Muslims in Singapore are considered as a minority, whereas Indonesian Muslims are the majority comprising the largest Muslim population in South East Asia and the world. These features make the research more interesting to be investigated.

7.3.1. Malaysia

Malaysia and Singapore share a similar history with the emergence of Islam in the 15th century. The Malacca Sultanate, founded by Parameswara, who later changed his name to Iskandar Shah, empowered the Malay Archipelago under its governance. That governance covered most territory of the Malay Peninsula – current West Malaysia including Singapore, the Riau islands and certain areas of the northern coast of Sumatera. The capital city, namely Malacca as its named in present-day Malaysia, grew as the most important entrepôrt for traders around the world such as Indians, Arabs and the Chinese.[707] It was part of the most important trade route in the world –

[706] Hilmar Farid, 'The Malay Question in Indonesia', *Inter-Asia Cultural Studies,* 18 (2017), pp. 317-325.

[707] Edward A. Alpers and Chaya Goswami, 'Transregional Trade and Traders: Situating Gujerat in the Indian Ocean from Early Times to 1900' in Ruby Maloni, *Gujarati Merchant Diaspora in South East Asia (Sixteenth and Seventeenth Centuries),* (Oxford University Press, 2019), p. 307. [Online] <https://www-oxfordscholarship-com.ezproxy.uwtsd.ac.uk/view/10.1093/oso/9780199490684.001.0001/oso-9780199490684-chapter-13> [accessed 30 October 2019].

known as the Silk Road – that connected the East and the West. Singapore was part of the route and the state governance of Iskandar Shah until the government was succeeded by the Sultanate of Johor. Islam was spread to Singapore the way it spread in Malaysia, i.e. via trade, marriage, conquest and preaching. Malacca became the most vibrant centre of Islamic learning and dissemination in this region. The teachings of Islam were broadened by the merchants from Arabia and India and later assimilated with Malay cultures.

Until today, Islam is strongly assimilated in the social, cultural and political structures of Malaysia. Since its independence in 1957, the status of Islam has been given due priority in the Federal Constitution. Article 3 states:

> Islam is the religion of the Federation; but other religions may be practiced in peace and harmony in any part of the Federation.[708]

The protection of Islam is guaranteed through the power of the rulers in each nine states out of the 13 states in Malaysia as the Head of Religion of Islam. In the other four states (Sabah, Sarawak, Malacca and Penang) and the three Federal Territories of Kuala Lumpur, Putrajaya and Labuan, the Head of Religion of Islam is constitutionally conferred by the Yang di-Pertuan Agong, the Supreme Head of the Federation.

The total population of Malaysia is 28.3 million as of the 2010 official census and 91.8 per cent were Malaysian citizens.[709] Of the resident population, Malay is the predominant ethnic group in the Peninsular of Malaysia at 63.1 per cent, followed by Chinese and Indian at 24.6 per cent and 7.3 per cent respectively. Malays are closely associated with Islam and recognised as Muslims. It is recorded in the Federal Constitution that Malay "means a person who professes the religion of Islam, habitually speaks the Malay language, conforms to Malay custom…"[710] Although not all Muslims are Malays, it is widely accepted that all Malays are Muslims.

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[708] The Commissioner of Law Revision Malaysia, *Federal Constitution*, trans. by The Commissioner of Law Revision, (Kuala Lumpur: 2010), p. 20.

[709] Department of Statistics Malaysia, *Population Distribution and Basic Demographic Characteristics* (Putrajaya: Department of Statistics Malaysia, 2011). It is recorded in the United Nations' unofficial statistics that the population in 2015 was 30.2 million. United Nations, *Worlds Population Prospects 2019,* 28 August 2019, <https://population.un.org/wpp/DataQuery/>, [accessed 31 October 2019]

[710] The Commissioner of Law Revision Malaysia, *Federal Constitution*, trans. by the Commissioner of Law Revision, (Kuala Lumpur: 2010), p. 153.

The uniqueness of Malaysia is its administration on Federal and State levels. There are certain aspects which fall solely under the jurisdiction of the federation or the authorities of each state, and certain others that fall under both authorities. Constitutionally, Islamic affairs are administered by the State in which the Head of Religion of Islam in each area is the Ruler of each state. Hence, each state has autonomy to manage all related issues of Islam within its own geographical boundaries. Although Muslims are united with the same source of its legal jurisprudence, a spectrum of variations in its administration exists. This uniqueness, though, requires coordination at the Federal level to ensure its effective governance across all 13 states and the Federal territories.

Therefore, the Department of Islamic Development Malaysia (abbreviated in Malay as JAKIM – *Jabatan Kemajuan Islam Malaysia*) was established at the federal level in 1968. It evolved from a single unit that was responsible to the National Council for Islamic Religious Affairs; to a sizeable organization under the Prime Minister's Department. JAKIM established the Shariah Expert Panel in 1991 to review various issues from an Islamic context. This panel comprises of 12 to 17 members, involving a number of Muftis and academicians from various Islamic sub-specializations. Any issues that affect national interests will be forwarded to the Fatwa Committee of the National Council for Islamic Religious Affairs. This Committee gathers all 14 Muftis of the States; nine experts appointed by the Conference of Rulers; JAKIM's Legal Advisor and JAKIM's Director General as the secretary. It is headed by a Chairman, currently Wan Zahidi Wan Teh. All decisions issued by the Fatwa Committee should be forwarded to the Conference of Rulers for their approval, and yet these decrees are not legally binding.

At the state level, each state has a State Council of Islamic Affairs, State Department of Islamic Affairs and Department of Mufti. All three departments play different roles within Islamic affairs. The Councils regulate policies on Islamic affairs. The policies are executed by the State Department of Islamic Affairs. The Department of Mufti is responsible for issuing fatwas and guidance on any contemporary issues and managing and conducting research on astronomy for setting up the Islamic calendar, daily prayer time and *qiblah* (direction towards *Kaʿbah* that Muslims should face during

prayer). Separation of power at federal and state level and differences of political power between the federation and certain states does have an impact on various aspects. However, it does not occur in managing issues related to health and medicine.

7.3.2. Singapore

Singapore is an island located south of the Peninsular of Malaysia and is connected to the state of Johor via the Malaysia-Singapore Second Link, also known as Tuas Second Link. The population of Singapore is 5.08 million as of the 2010 and comprised of Chinese, the largest community, at 74 per cent of resident population, as well as Malay and Indian, comprised of 13.3 per cent and 9.2 per cent of resident population, respectively, based on the 2010 Singapore's census.[711] Muslims are comprised of 98.7 per cent of Malays and 21.7 per cent of Indians. No Chinese identified as Muslim. These number account for 14.7 per cent of Muslims in the total resident population by religious group. It indicates that Malays and Muslims are the second largest group of community in Singapore and remain as a minority.

After decades of political struggle, Singapore achieved its independence in 1965 from Malaysia. The government applies English law and statues based on the application of English Law Act 1993. The Head of State is a President who is directly elected by the people. The President possesses certain veto powers over the government at the discretion of the Constitution in certain circumstances. Outside of those areas, the President should act according to the Cabinet's advice. Currently, Madam Halimah Yaacob is President, she was elected unopposed. For the first time in 54 years of Singapore's governance, there is a female President and she is the second Malay Muslim President. The first was Yusof bin Ishak (1965 – 1970). The Head of the Government or Leader of the Executive branch is the Prime Minister, currently Mr Lee Hsien Loong.

[711] Singapore Department of Statistics, *Census of Population 2010 - Advance Census Release* (Singapore: Department of Statistics, Ministry of Trade and Industry, 2010), p. 5. It is recorded in the United Nations' unofficial statistics that the population in 2015 was 5.5 million. See further details in United Nations, *Worlds Population Prospects 2019*.

The government practices secular governance, in which religion is kept separate from political agendas. The Prime Minister's speech was quoted on National Rally Day pertaining to religion and society:

> "… The government has to remain secular. The government authority comes from the people. The laws are passed by Parliament elected by the people. They do not come from a sacred book. The government has to be neutral, fair. We are not against religion. We uphold sound moral values. We hold the ring so that all groups can practice their faiths freely without colliding with one another in Singapore. And that is the way Singapore has to be."[712]

In a multi-ethnic and multi-religious society, the struggle to keep the society living peacefully and harmony is real. Hence, the government stands on secular policies, yet permits the religious groups to contribute to nation building in terms of preparing the communities with ethics and moral values.

Article 12 of Singapore's Constitution provides equal protection for all citizens and protects against any discrimination on the basis of religion, race, descent or place of birth.[713] There shall be no discrimination based on the same grounds, with regard to the right in respect of education as articulated in Article 16 (1). Additionally, Article 15 (1) guarantees every person's right to profess, practice and propagate his/her religion. However, no person should be imposed to perform or participate in any ceremony or worshipping act of religion other than his/her own belief as stated in Article 16 (3). But the religion of child, under the age of 18, is decided by his/her parent or guardian.

Despite having the right to freedom of speech, expression and peaceful assembly, Singaporeans also have the right to form associations, which implicitly includes forming religious associations, as understood in Article 14 of the Constitution. Religious groups, according to Article 15 (2), also have the right to manage their own affairs, establish and maintain their own institutions as well as to acquire their own property and administer it according to the law. Subsequently, all religious groups are permitted, by law, to establish their own educational institutions without any discrimination based on religion as assured by Article 16 (3) of the Constitution.

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[712] Lee Hsien Loong, *Prime Minister Lee Hsien Loong's National Rally Day 2009 Speech,* (Singapore: Prime Minister's Office, 2009) <https://www.pmo.gov.sg/Newsroom/prime-minister-lee-hsien-loongs-national-day-rally-2009-speech-english> [accessed 5 August 2019].

[713] Republic of Singapore, *Constitution of the Republic of Singapore,* ed. by Attorney-General of Singapore, (Singapore: Constitution, 1 July 1999).

Even though Singapore is a secular state and dominated by the Chinese community, Malays and Islam have special reference in its Constitution. Article 152 clearly states that the government recognises the special position of Malays, who are the indigenous people of Singapore. Therefore, the government is obliged to protect, foster and promote their political, educational, religious, economic, social and cultural interests. In addition, the Malay language is recognised as the national language, despite acknowledging English, Mandarin and Tamil as other official languages.

Islam or the 'Muslim religion' has been given provision in Article 153 of the Constitution to regulate Muslim affairs and to establish a council to advice the President in matters related to Islam.[714] The Administration of Muslim Law Act (AMLA) was regulated in 1965. The Act enshrines the jurisdictions of the Muslim council, named The Islamic Religious Council of Singapore (MUIS – *Majlis Ugama Islam Singapura*) to encompass matters related to the Shariah Court, financial provisions, mosques and religious schools, halal and hajj (pilgrimage) matters, marriage and divorce, property, conversion and other related matters. Other organizations established to cater for issues related to Muslim affairs are the Shariah Court and Registry of Muslim Marriage (ROMM).

MUIS was established in 1968 after AMLA came into effect. It is a statutory body overseen by the Ministry of Culture, Community and Youth, led by its Minister, Ms Grace Fu Hai Yien. The Council is comprised of 19 members including the President of MUIS, Mr. Mohamad Alami Musa, the Mufti, Dr. Nazirudin Mohd Nasir, the Chief Executive, Mr. Esa Masood and other appointed members recommended by the Minister and appointed by Muslim organisations that represent all Muslims. One of MUIS's functions is issuing fatwas on current issues. While the government likes to separate religion from politics, MUIS is looked upon as the state control over religious bodies.[715] All key office-bearers in the MUIS including the Mufti are appointed by the President with the recommendation of the Prime Minister.

[714] Republic of Singapore, 1999.
[715] Lily Zubaidah Rahim, 'Governing Muslims in Singapore's Secular Authoritarian State', *Australian Journal of International Affairs*, 66 (2012), p. 172.

Under the auspices of MUIS, the Office of the Mufti acts as the secretariat for the Fatwa Committee in managing operational duties for the issuance of fatwas. The functions of the MUIS and Fatwa Committee are seen as bridging the gap between Islam and science. The aforementioned information will enlighten us on Islam and Islamic authority in the secular state of Singapore.

7.3.2.1. Indonesia

The Republic of Indonesia is a neighbouring country to Malaysia and Singapore. The largest archipelago nation in the world is situated to the south of Singapore, with some parts attached with the West Peninsular of Malaysia. It has a 226 million population of which 87 per cent are Muslims.[716] This is the largest Muslim population in one country, in the world, at approximately 200 million. The second largest religion adhered to is Christianity at about 7 per cent, followed by Hinduism and Buddhism. Across this population, there are 633 ethnic groups and up to 1,000 sub-ethnic groups. One of these diverse ethnic groups is the Malay community, which historically experienced transformation over the years, when the issue of unity was highly required to build up 'one land, one nation and one language, Indonesia'. [717]

Indonesia has over 18,000 islands that shape the beautiful combination scenery of water and mountains. This unique geography explains why Indonesia has so many ethnic groups. It also lies in the 'Ring of Fire' and experiences frequent earthquakes and volcanoes, other frequent natural disasters include severe drought, tsunami, occasional floods and forest fires.

The governance of Indonesia is divided into 31 provincial (*propinsi*) levels, autonomous provinces (Aceh), one special region (Yogyakarta) and one special capital city region (Jakarta). Provinces are divided into municipalities (*kota*) in urban areas and regencies (*kabupaten*) in rural areas. All of them are united with one philosophical foundation known as *Pancasila* which emphasizes 'Believe in One God

[716] Indonesia, *Badan Pusat Statistik (Central Statistical Department)*, 2019 (Indonesia: Central Statistical Department) <https://sp2010.bps.go.id> [accessed 7 July 2019]. It is recorded in the United Nations' unofficial statistics that the population in 2015 was 258 million. See further details in United Nations, *Worlds Population Prospects 2019*.

[717] Hilmar Farid, 2017, p. 320.

the Almighty' as its first element. Unlike Singapore, Indonesia forms a nation state on a spiritual basis.

The 1945 Constitution of the Republic of Indonesia recognized Islam as its basis, which is identified in Chapter XI, article 29: 'The State shall be based upon the belief in the One and Only God'. In order to secure peace and harmony of the country, freedom of religion of Muslim and non-Muslim is also guaranteed as articulated in Chapter XA, article 28E, 28I and Chapter XI, article 29.[718] In order to maintain the welfare of other religions, The Ministry of Religious Affairs was established even the percentage of non-Muslims in the population is small. Five Directorate Generals representing Islam, Catholicism, Protestantism, Hinduism and Buddhism are the core of the Ministry.

The development and administration of Islamic affairs is affected by the erratic political changes in the Republic of Indonesia. The history of the existence of Islam, along with the struggle to keep the stability of the country, shows the active participation of Islamic scholars in political affairs whether in government, political parties, Islamic organizations or even in rebellions against central authority.[719] For instance, Abdurrahman Wahid, a grandson of the founder of *Nahdatul Ulama*, the largest traditionalist organisation, was elected as the President from 1999 to 2001.[720] During his tenure, Amien Rais, one of the leaders of *Muhammadiyah*, a reformist organisation was elected to be the Chairman of the People's Consultative Assembly until 2004.[721] Both Islamic organisations have a long history in Indonesian civil society, gain strong

[718] Indonesia, *Undang-Undang Dasar Negara Republik Indonesia Tahun 1945 (the 1945 Constitution of the Republic of Indonesia),* (Indonesia: 1945).

[719] Moch Nur Ichwan, 'ʿUlamāʾ, State and Politics: Majelis Ulama Indonesia after Suharto', *Islamic Law and Society*, 12 (2005), pp. 45-72.

[720] Inspired by the confrontation against a movement to abolish various sects other than Wahabism that happened in Mecca, Kyai Haji Hasyim Asy'ari established an organization known as Nahdatul Ulama on 31 January 1926. This movement focuses more on preserving traditionalist approach and balancing between rationalist and scripturalist extremism. See further details in NU Online, 'Sejarah (History)', 2019, <https://www.nu.or.id/static/6/sejarah-nu> [accessed 15 September 2019].

[721] Muhammadiyah was pioneered by Kyai Haji Ahmad Dahlan, a Muslim merchant and a sermon reader during Friday prayers for Kraton Yogyakarta Sultanate. Muhammadiyah was established in 18 November 1912 at Kauman Yogyakarta, Indonesia. It is an Islamic movement that aims to spread the teaching of Islam and characterise itself as a reformist movement. See further details in Muhammadiyah, 'Sejarah Muhammadiyah (History of Muhammadiyah)', 1997, <http://www.muhammadiyah.or.id/id/content-50-det-sejarah.html> [accessed 15 September 2019].

influence over millions of members and operate their own infrastructure such as Islamic boarding schools, mosques and hospitals.

Islam in Indonesia faces a discursive development against syncretism, pluralism, liberalism and secularism.[722] During the regime of Suharto (1966 – 1998), the Council of Indonesian Scholars (MUI – *Majelis Ulama Indonesia*) was established in 1975. The proposal of its establishment was rebuffed initially by the society as it was seen as a stratagem to eliminate Islamic political power. Later, Haji Abdul Malik Karim Amrullah (known as Hamka) (d. 1981) was appointed to be its first leader with the objective to unite Muslim communities and to assist the government in combating ideologies that go awry from genuine Islamic teachings.[723] The core jurisdiction of MUI is to provide guidance and fatwas for public reference, guidelines and practices.

The MUI (Council of Indonesian Scholars) is a non-governmental institution and not a statutory body governed by law. The chairperson is not appointed by the government but selected by its members, who include scholars from *Nahdatul Ulama, Muhammadiyah*, and other organisations.[724] MUI's headquarters operates in Jakarta, the capital city of Indonesia. It has established offices in all provinces, a number of municipalities/regencies and districts.[725] Any decision or fatwa issued by the provincial MUI should comply with the central MUI's decisions unless the latter permits different decisions after a consultation required due to dissimilar circumstances.

Figure 7 summarizes the Islamic authorities altogether in these three countries, who are the actors that being examined in this chapter.

[722] Carool Kersten, *Islam in Indonesia: The Contest for Society, Ideas and Values* (New York: Oxford University Press, 2015), p. 5.

[723] Mohamad Atho Mudzhar, *Fatwa-Fatwa Majelis Ulama Indonesia (MUI) Mengenai Masalah-Masalah Bioetika Tahun 1975 - 2011 (Fatwas of Council of Indonesian Scholars -MUI- regarding Bioethical Issues 1975 - 2011),* Muzakarah Ulama MABIMS on Bioethics and Regional Development of Islamic Laws, (Singapore: Islamic Religious Council of Singapore, 2012), p. 3. Hamka was a respected Indonesian Islamic scholar and philosopher in Southeast Asia. His 134 scholarly writings influenced much of the thought and ideology of the society. His most renowned writing is Tafsir al-Azhar, a commentary on the Qurʾān.

[724] Moch Nur Ichwan, 2005, p. 45; Mohamad Atho Mudzhar, p. 4.

[725] Mohamad Atho Mudzhar, 2012, p. 3.

Figure 7: Islamic Authorities in Malaysia, Singapore and Indonesia

7.4. Practice of Islamic Bioethics in Malaysia, Singapore and Indonesia

7.4.1. Malaysia

In the ninth century, prior to spread of Islam in South East Asia, the Malay community, whether Muslims or not, embraced their own traditional or customary system called *adat* like in such thing as marriage and healing.[726] The practices of *adat* are not without *budi,* 'a set of internal values that shape one's mentality and personality'.[727] *Budi* encompasses values including compromise, tolerance, modesty and forgiveness that later become binding principles in shaping a Malays' character.

In the fifteenth century, after the arrival of Islam, Malays' *adat* and *budi* were incorporated within Islamic values progressively, letting Islam be an overarching framework of beliefs in Malay society. Sharī'ah was introduced to them through traditional Islamic learning centres (*pondok*), eliminating the customs that were at odds

[726] Wan Norhasniah Wan Husin, "Budi-Islam': It's Role in the Construction of Malay Identity in Malaysia, *International Journal of Humanities and Social Science,* 1 (September 2011), pp. 132-142; Sharifah Zaleha Syed Hassan, 'A Fresh Look at Islam and Adat in Malay Society', *Sari 18,* (2000), pp. 23-32.
[727] Wan Norhasniah Wan Husin, p. 132.

with Islamic teaching. The Malay words *adat*, *adab*, *akhlak*, *budi*, *syariah* and *fiqh* – rooted from Arabic – are interconnected terms which are commonly used to define what is right and what is wrong, instead of using the word ethics.[728] One of the famous sayings among the Malays that portrays their connection is:

> *Adat bersendikan hukum*
> *Hukum bersendikan syara'*
> *Syarak bersendikan Kitabullah*
> *Syara' mengata, adat memakai*
> *Ya kata syara', benar kata adat.*

This can be translated as:[729]

> *Adat* built on (Islamic) rulings
> (Islamic) rulings built on *sharīʿah*
> *Sharīʿah* built on the Holy Book (the Qurʾān)
> *Sharīʿah* dictates, *adat* practices
> If *sharīʿah* says yes, *adat* will follow.

The relationship between ethics in Malay customs and sharīʿah makes this research significant. As Malays are the indigenous group of Malaysia, the spreading of this understanding dominates and shapes the practices in this country. However, other religious beliefs are always taken into consideration in regulating any policies and laws. In an interview conducted with the Deputy Director of Family Health Services Division, Ministry of Health, she reiterated that:

> "Basically, KKM (*Kementerian Kesihatan Malaysia* – Ministry of Health) never discriminates against any patients to get the treatment. KKM will always protect the issue from being spread, respect the patients' confidentiality and provide the services without being judgmental (due to religion)."[730]

Bioethics was formally institutionalized in 2010 through the establishment of 'Majlis Bioetika Negara' or The National Bioethics Council. Their role is important as an advisory body to manage issues related to health, environment, culture, laws, religions and society.[731] Through this establishment, Islamic perspectives are embedded and

[728] Noor Munirah Isa and others, 'Bioethics in the Malay-Muslim Community in Malaysia: A Study on the Formulation of Fatwa on Genetically Modified Food by the National Fatwa Council', *Developing World Bioethics*, 15 (April 2014), 143-51, p. 145.

[729] The translation is provided by the researcher as Malay is her mother tongue and English is the second language.

[730] Faridah Abu Bakar, *Email to Taqwa Zabidi* (8 September 2016).

[731] Ministry of Science and Technology, *Majlis Bioetika Negara (National Bioethics Council)*, <www.bioetika.gov.my>, 2017.

deliberated via numerous publications with the cooperation of Islamic organizations such as Institute of Islamic Understanding Malaysia (IKIM) and Department of Islamic Development Malaysia (JAKIM).

As the representative of JAKIM in the National Transplantation Council, the researcher herself witnessed the use of bioethics in decision-making process. Members of the Council also include representatives from other religious groups, i.e. Christianity, Hinduism and Buddhism. The meeting points of all aspects including medical, health, laws, ethics and religious perspectives furnished the regulations on organ donation and transplantation holistically. An Islamic underpinning has become the main construction of the ethical concepts through the fatwas provided by the Fatwa Committee, at the state level, and the juristic opinions issued by the Fatwa Committee of the National Council for Islamic Religious Affairs.

7.4.2. Singapore

The biomedical sciences have been identified as the fourth Singaporean economic pillar. It includes four domains, namely: pharmaceuticals, medical technology, and biotechnology and healthcare services. As mentioned above, Singapore practices the separation of religion and state. This includes in medical ethics policies. There are no recommendations being made to amalgamate biomedical ethics with religion. The patient's belief, culture and religion may be taken into consideration by a doctor in building up a good relationship and providing a sound treatment to meet the patient's best interests.[732] However, in making such decisions, the doctor's decisions "ought to be based on an objective assessment of clinical needs and likely effectiveness of treatment options".[733] Religion may have an influence on the decision-making process, but the doctor should not recognise religion as an element of decision-making. This is clearly noted in a pledge issued by the Singapore Medical Council:

> "I solemnly pledge to … not allow the consideration of race, religion, nationality or social standing to intervene between my duty and my patient…"[734]

[732] *Handbook on Medical Ethics*, ed. by Singapore Medical Council, (Singapore: Singapore Medical Council, 2016), p. 11.
[733] Singapore Medical Council, *Handbook on Medical Ethics*, 2016, p. 33.
[734] Singapore Medical Council, *Ethical Code and Ethical Guidelines* (Singapore: Singapore Medical Council, 2016), p. 10.

This pledge is based on the *Declaration of Geneva* and represents the set of ethical values contained in the Ethical Code and Ethical Guidelines of Singapore.[735] Every doctor has to make this pledge upon his/her registration with the Singapore Medical Council.

Around the world, belief, culture and religion remain challenges in biomedical ethics. Therefore, the Bioethics Advisory Committee (BAC) in Singapore was established in December 2000 to advise the government on ethical, legal and social issues arising from research on human biology and behaviour. The BAC also is expected to develop and recommend policies on ethical, legal and social issues in order to protect the welfare of the public and yet allowing a progressive development of science and technology. The BAC is comprised of 13 professionals. One of them was Dr. Nazirudin bin Mohd Nasir, when he was a Senior Director of Religious Policy and Development at the MUIS. The appointment of a MUIS representative to the BAC indicates that there is an appropriate platform to raise any ethical issues faced by Muslim communities and to recommend solutions from Islamic points of view.

A number of medical issues have been discussed by the Fatwa Committee, including family planning and reproductive technology, organ donation and transplantation, science and biomedical research using human tissue as well as medicine, health and treatment.[736] Singapore adopts the concept of *iftāʾ jamāʿī* (collective fatwa) through consultative discussion to achieve a unanimous decision on emerging issues with members of the Fatwa Committee.[737] The Mufti is regard as the Chair of the Committee, while the members include two appointed officers among members of the MUIS Council and another two independent scholars, who are not related to the MUIS Council. Later, membership was expanded by the appointment of other local religious teachers and scholars. This is to achieve the purpose of enriching the discussion and training the younger members of the Council who may serve the Fatwa Committee, in the future.

[735] Singapore Medical Council, *Ethical Code and Ethical Guidelines*, p. 2.
[736] *Fatwas of Singapore: Science, Medicine and Health*, ed. by Naziruddin Mohd Nasir (Singapore: Majlis Ugama Islam Singapura, 2017) <https://muisfatwa.pressbooks.com>.
[737] Naziruddin Mohd Nasir, para 34 of 53.

Being a member of a Fatwa Committee in a developed country like Singapore requires high commitment and expeditious talent to cope with a rapidly changing and dynamic environment while maintaining the basic framework of sharīʿah. Furthermore, fatwas play an important role in every Muslim's life especially in a secular, multi-ethnic and multi-religious setting. Therefore, every member should prepare themselves in terms of scholarship and expertise in various new fields and industries such as economics, science, medicine, politics, ethics and others. Medicine and health are undoubtedly important aspects.

According to the former Mufti, Fatris Bakaram, MUIS works under the jurisdiction as articulated in AMLA. Any act beyond the jurisdiction should not be exercised unless the government requires such advice as a guideline or reference. It relies on the government's authority whether to adopt the statement as a legal provision or for it to remain as a mere reference.[738]

7.4.3. Indonesia

The development of biotechnology requires a specific focus on bioethical issues. This is due to the fact that manipulation of national resources through technological advancement may lead to disaster if it progresses without boundaries. Ethics, therefore, is mandatory to ensure sustainability of technology and the state of humanity's well-being within the context of moral values and religious perspectives. In Indonesia, Islam is the main religion practiced by the majority of the population. Therefore, Islam has a great influence on Indonesian laws and regulations, including health, technology and the medical field.

Islam's influence in the development of biotechnology ethics is observed through its national legislation. This can be seen through four related laws. Firstly, in the 1945 Constitution of the Republic of Indonesia, which states that the first element of the Five Principles of the country - known as Pancasila - as 'Belief in One God the Almighty'. This shows the basic pillar of Indonesian legislative and executive roles is based on

[738] Fatris Bakaram, *Conversation with Taqwa Zabidi* (23 March 2017).

Islamic teaching. Although Indonesians are free to hold on to and practice any religious beliefs, Islam has been placed as its governmental basis.[739]

Further, article 31(5) of this Constitution states that:

> "The government develops knowledge and technology by upholding religious values and national unity for the purpose of progression of civilization and human welfare."[740]

The Constitution itself makes it clear that expansion of knowledge and technology is appreciated and embraced by the country. Yet, religion plays important roles in ensuring the interests of the State.

Referring to Act No. 18, 2002 pertaining to The National System of Research, Development and Application of Knowledge and Technology, it goes further to consider:

> "The universe and everything in it are created by God the Almighty for the benefit of human within which their management and application necessitate expertise, utilization and advancement of science and technology in a responsible manner."[741]

In the Indonesian Code of Medical Ethics (*Kode Etik Kedokteran Indonesia*), religion is inseparable from the regulations. It does acknowledge practices and beliefs of other religions while emphasizing Islam as the main pillar. For example, the oath for all medical providers begins with the proclamation of "In the name of Allah, I solemnly pledge…" Whilst, for non-Muslim medical providers, they should begin with the proclamation based on their own religions.[742]

Although the Oath states that any decision should not be influenced by religion or any other non-medical factors, the regulations are based on Islamic teachings. For instance, abortion and euthanasia are medically prohibited due to the fact that only

[739] Indonesia, *Undang-Undang Dasar Negara Republik Indonesia Tahun 1945 (the 1945 Constitution of Republic of Indonesia),* (Indonesia: 1945), p. 30.

[740] Indonesia, p. 31. The translation in English was provided by the researcher herself.

[741] Indonesia, *Undang-Undang Republik Indonesia (the Law of the Republic of Indonesia),* National System of Research, Development and Application of Knowledge and Technology, 18 (Indonesia: 2002), p. 1.

[742] *Kode Etik Kedokteran Indonesia (Indonesia Code of Medical Ethics)*, ed. by Agus Purawadianto and others (Jakarta: Ikatan Dokter Indonesia, 2012), p. 8.

Allah has the right over human's life and death.[743] Every medical provider also should understand that only Allah has the ability to cure illnesses and that the knowledge, skills and expertise they hold are the gifts of Allah for them. The reminder of God as the Creator of the universe and the benefits of His creations for humankind, commands Muslims on how they should act and behave ethically.

Consequently, the Indonesian National Bioethics Commission or '*Komisi Bioetika Nasional*' was established in 2009 focusing on three main scopes, namely medicine, health and animal welfare. Some of the biomedical issues discussed through this Committee have been incorporated in the national laws. It is significant that the legal statement seems to consider decisions made by the Council of Indonesian Scholars (MUI). Between 1975 and 2011, Jakarta recorded that there were eight fatwas produced by the MUI pertaining to bioethical issues including cornea transplantation, artificial insemination, heart valve transplantation, cloning, the use of human organ in drugs manufacturing, embryo transplantation, organ banks and the consumption of microbes in food.[744] Mohamad Atho Mudzhar, former Rector of Syarif Hidayatullah State Islamic University, noted that some of instituted national laws are influenced by the fatwas of the MUI.[745]

For instance, the Law on Health (*Undang-undang Kesehatan Republik Indonesia Nomor 36 Tahun 2009*) explicates on organ transplantation and clause 65 (2) mentions the importance of getting permission of the donor and/or the next of kin before removing body parts.[746] This passage on donation is also highlighted in the MUI's decree issued on 27 June 1987.[747] However, the adoption of fatwa decree is not the sole contributor to the regulation of the law, since the same practice of getting

[743] Agus Purawadianto and others, p. 38. The understanding is based on the Divine texts of the Qurʾān and Ḥadīth on the prohibition of killing others except for just cause as mentioned in the *Sūrah al-Furqān* (The Criterion), 25: 68 and a number of verses explicate Allah's dominion over such life as reiterated in *Sūrah Yūnus* (Jonah), 10: 31 and *Sūrah Al-Anʿām* (The Cattle), 6: 95.

[744] Majelis Ulama Indonesia, *Himpunan Fatwa MUI (Collections of MUI Fatwa)*, ed. by Hijrah Saputra, Andriansyah and Andhika Prasetya K. S. Sos (Indonesia: Erlangga, 2011).

[745] Mohamad Atho Mudzhar, p. 6.

[746] Indonesia, *Undang-Undang Republik Indonesia Nomor 36 Tahun 2009 Tentang Kesehatan (Law of Republic of Indonesia no. 36, 2009 on Health)*, trans. by Ministry of Law and Human Rights Indonesia, (Republic of Indonesia: 2009), p. 26.

[747] Majelis Ulama Indonesia, p. 619.

the permission of the donor and/or the next of kin is also found in the international guideline.

The clearer evidence of the influence of fatwas in the regulation of the law is pertaining to abortion. In 2005 the MUI discussed abortion, due to increasing unsafe practices within the communities. It is clear that the Law on Health, which was regulated four years later, adopted almost all conditions of abortion issued by the MUI in clause 75, depicting the MUI's influence on the national law.[748] While the main issues were adopted in national laws, other statements are embedded in related manuals or operating procedures.

7.5. Roles of Islamic Authorities over Issues of Gender Ambiguity

For the purpose of determining the need of the involvement of religious leaders in a Multi-Disciplinary Team in managing patients with DSD, three main roles pertaining to the issue of gender ambiguity were explored further. These included regulating fatwas related to gender ambiguity, providing necessary advices and guidance for patients and doctors and supporting other related agencies in administrative roles.

7.5.1. Regulating Fatwas

One of the important roles of Islamic authorities, particularly mufti or jurist consultant, is regulating fatwas on any related issues over gender ambiguity. Research conducted elsewhere found 14 fatwas provided by nine juristic councils around the globe discussing issues related to gender ambiguity.[749] Among these fatwas are those provided by juristic councils in Malaysia and Indonesia. In Malaysia, between 1982 and 2006, there were three issues tabled to the Fatwa Committee. In the 4th Conference, which was conducted on 13 and 14 April 1982, the Fatwa Committee decided that sex change is prohibited in Islam and a person will remain as gender at birth even after underwent a surgical operation. This prohibition is excluded for intractable *khunthā* who possesses dual genitalia in order to retain the functional

[748] Indonesia, *Undang-Undang Republik Indonesia Nomor 36 Tahun 2009,* p. 26.

[749] Taqwa Zabidi, 'Analytical Review of Contemporary Fatwas in Resolving Biomedical Issues Over Gender Ambiguity', *Journal Religion of Health* (58) (2019): 153 – 167, p. 160.

genitalia and remove the other non-functional genitalia.[750] Again, in the 25th Conference organised on 13 December 1989, the decisions emphasized that the sex change is prohibited for transvestites. However, for those who born as *khunthā mushkil*, it is permissible to 'undergo surgery to retain the most functional private part'.[751]

However, the complexity of DSD cases called for the Ministry of Health to seek further revision of these decisions. Hence, on 21 – 23 November 2006, the 76th Conference of the Fatwa Committee issued a thorough decision on Congenital Adrenal Hyperplasia and Testicular Feminization Syndrome (TFS), also known as Androgen Insensitivity Syndrome (AIS), as follows:[752]

i. For a Congenital Adrenal Hyperplasia (CAH) reared male, gender reassignment surgery to get back to the previous gender (female) is permitted in Islam because this can be accomplished by hormone treatment and surgery;
ii. Meanwhile, for Testicular Feminization Syndrome (TFS), getting back to the male gender through surgery or hormone treatment is quite difficult. If the patient intends to undergo surgery, it is permitted provided that the surgery does not harm the patient psychologically and biologically;
iii. For the case of TFS detected after the person is already mature, the person can continue a normal life and the gender is recognized from his/her physical form and the explicit form of the genitalia. Surgery to remove the testss (if any) is permissible to prevent the risk of cancer. The marriage of a person with a spouse who suffers TFS need not to be dissolved;
iv. Medical specialists should give explanations and advice to parents and Muslim individuals who suffer from CAH and TFS to undergo treatment in order to avoid any religious issues.

[750] The researcher is of the opinion that this decision should be reviewed particularly on the definition of intractable *khunthā* which is assumed to have dual genitalia and its implication on the rulings of sex change for them. The former was elaborated in Chapter 3 on misinterpretation of the meaning of intractable *khunthā* and the latter was discussed in Chapter 5, in which they are not permissible to conduct sex change since the dominant gender is not prevailed.

[751] Department of Islamic Development Malaysia, *Decision of the Fatwa Committee of the National Council for Islamic Religious Affairs Malaysia* (Putrajaya: Department of Islamic Development Malaysia, 2010), p. 123-124.

[752] Department of Islamic Development Malaysia, pp. 74-75.

Zainuddin stated that this fatwa provides guidelines for managing her CAH patients on issues of gonadectomy, sex reassignment surgery and maintaining patients' marital relationships.[753] Jalaludin argued for more general fatwas for two reasons. Firstly, a fatwa is recognised as a guidance instead of a deciding factor. Secondly, each case is unique and a fatwa cannot be a binding blanket solution. A broader and medical-nomenclatured fatwa would be sufficient as guidance for practitioners.[754]

In Malaysia, personal cases are not tabled at Fatwa Committee of the National Council for Islamic Religious Affairs. This is because any decision made by the Fatwa Committee is publicised for public reference, but personal cases should be kept under wraps. Therefore, individual DSD cases are discussed by the Shariah Expert Panel. There were five cases discussed in 2011, 2014, 2015, 2017 and 2018, as shown in Table 10. Case of BB involved sex reassignment from male to female; case CC remained as gender at birth, i.e. female; and other cases involved sex reassignment from female to male. These cases were forwarded by the tertiary hospitals, whose doctors are members of the MDT led by Zainuddin, as described in the previous chapter. A JAKIM officer was appointed as a member of the MDT in order to provide preliminary advice for the doctors from the Islamic viewpoint and to assist members of the Shariah Expert Panel to get a better comprehension of the cases.

The specific conditions of these cases have been described throughout of this research as cases in point. JAKIM, through Shariah Expert Panel, plays its role in seeking the Islamic juridical ruling on sex assignment and the treatment as well as supporting the application of sex change status to the National Registry Department. For case AA and CC, JAKIM extended its role to advising patients on performing religious obligations, marital issues and family conflict that raised due to lack of understanding of this condition among family members.

[753] Ani Amelia Zainuddin, *Skype Conversation with Taqwa Zabidi*.
[754] Yazid Jalaludin, *Telephone Conversation with Taqwa Zabidi.*

Table 10: Cases of Disorders of Sex Development that Were Analysed by the Shariah Expert Panel between 2011 and 2018

No.	Patient	Year	Issues	Decision of Shariah Expert Panel		Source
				Sex (Re)assignment	Sex Change Status	
1	AA	2011	46XX DSD - Salt wasting CAH. Male sexual secondary characteristics developed.	Female to male	Yes	Taqwa Zabidi, 2016[755]
2	BB	2014	Sex chromosome DSD - Mixed gonadal dysgenesis. Have both ovary (female) and testis (male).	Male to female	Yes	Taqwa Zabidi, 2014[756]
3	CC	2015	Sex change prior to conversion to Islam. Female sexual secondary characteristics.	Remain female	No	Ahmad Tarmizi Mahmud, 2015[757]
4	DD	2017	46XY DSD - 5α reductase deficiency Perineoscrotal hypospadias (akin to female genitalia) Male sexual secondary characteristics.	Female to male	Yes	Taqwa Zabidi, 2017[758]
5	EE	2018	46XY DSD - 5α reductase deficiency Perineoscrotal hypospadias (akin to female genitalia) Male sexual secondary characteristics.	Female to male	Yes	Taqwa Zabidi, 2018[759]

Meanwhile, in Singapore, Bakaram explained that since the 1970s, there has been no specific fatwa issued on the management of patients with DSDs. Nine fatwas were issued between 1976 and 2005 on sex operations and the roles of authority in relation to transsexual cases as summarised in Table 11. Five fatwas were requested in 1976, 1984, 1989, 1993 and 1997 with regard to sex change operations.

[755] Taqwa Zabidi, Ani Amelia Zainuddin and Bettina E. Schmidt, 'An Analysis of Islamic Biomedical Ethics in Managing Patients with Disorders of Sex Development: An Experience in Malaysia', *Medicine and Law*, 35 (2016), pp. 345-364.

[756] Taqwa Zabidi, *Hukum Penetapan Jantina Bagi Pesakit Mixed Karyotype (Rulings on Gender Assignment for Patient with Mixed Karyotype)*, Kertas Kerja Mesyuarat Panel Pakar Syariah Jabatan Kemajuan Islam Malaysia (Paperwork of Shariah Expert Panel Meeting, Department of Islamic Development Malaysia), vol. 86 (Putrajaya: 2014), 1-36, p. 1.

[757] Ahmad Tarmizi Mahmud, *Hukum Penetapan Jantina Bagi Pesakit H (Rulings on Gender Assignment for H)*, Kertas Kerja Mesyuarat Panel Pakar Syariah Jabatan Kemajuan Islam Malaysia (Paperwork of Shariah Expert Panel Meeting, Department of Islamic Development Malaysia), vol. 88 (Putrajaya: 2015), 1-36, p. 1

[758] Taqwa Zabidi, *Hukum Penetapan Jantina Bagi Pesakit N.E.S (Rulings on Gender Assignment for N.E.S)*, Kertas Kerja Mesyuarat Panel Pakar Syariah Jabatan Kemajuan Islam Malaysia (Paperwork of Shariah Expert Panel Meeting, Department of Islamic Development Malaysia), vol. 96 (Putrajaya: 2017), 1-24, p. 1.

[759] Taqwa Zabidi, *Hukum Penetapan Jantina Bagi Pesakit N.A.R (Rulings on Gender Assignment for N.A.R)*, Kertas Kerja Mesyuarat Panel Pakar Syariah Jabatan Kemajuan Islam Malaysia (Paperwork of Shariah Expert Panel Meeting, Department of Islamic Development Malaysia), vol. 98 (Putrajaya: 2018), 1-22, p. 1.

The first fatwa endorsed in relation to sex change was on 22 January 1976. It refers to the case of a converted Muslim who changed the gender prior to the conversion. The Mufti discussed with physicians to confirm the sex at birth and to identify any sexual differentiation. However, the result showed that the patient was a male and the sex change was due to a behavioural crisis. This case was not related to sexual disorders. Therefore, the person remained identified as male but his conversion to Islam was not affected. This initial fatwa shows that the Fatwa Committee carefully investigated the case with the engagement of the physicians. It became precedence for other cases referred to the Office of the Mufti.

This first case became the precedent case for the rest of the cases. In 1984, a person requested a sex change confirmation due to conversion to Islam and marriage. Similar to the first case, the operation was prohibited, the conversion was accepted according to the initial gender and the marriage was dissolved. The same decision was seen in the third case in 1989 without the question on marriage. Cases discussed in 1993 and 1997 were related to *khunthā.* Sex reassignment for these cases were accepted based on Aḥmad Sharbaṣī's opinion on the permissibility to eliminate obscured gender. These decisions were required particularly to fulfil the role of the Islamic authority's jurisdiction on marriage. It is the ordinary role of the Islamic authority to handle the registration of marriage based on sharīʿah principles. Muslim patients do not expect an intervening role by the Islamic authority with regard to sex reassignment from bioethical aspect. Reasons for this are beyond the scope of this research.

In 1995, there were two cases. In July 1995, Mufti's was referred to on eligible person for bathing ritual for corpse of a transsexual. The Fatwa Committee decided that the person to perform ritual bath is to follow the sex at birth of the corpse. In case there is no person with the same sex who would like to carry out the duty, the deceased's family is highly recommended to manage the body. Two months later, an issue arose in Egypt related to sex change operation conducted on a student of University of Al-Azhar. At that time, Muslims in Singapore requested further clarification from the Office of the Mufti. Subsequently, the Office of the Mufti released a statement clarifying the situation following the discussion with Egypt's Grand Mufti.

In 2000 and 2005, two enquiries were forwarded to the Office of the Mufti. These did not directly relate to DSD cases. The former enquiry was on prenatal sex assignment and decision had been made that the effort of sex selection is allowed as it does not overrule Allah's predestine. The second enquiry was on the role of authority on handling marriage of Muslim and non-Muslim transsexuals. The decision held that Muslim officers are not allowed to manage the marriage of transsexuals.

Table 11: Summary of Fatwas Regarding Sex Change Operations in Singapore between 1976 and 2016

No.	Year	Issue	Patient With DSD	Result of Fatwa
1	1976 (22, Jan)	Sex change operation (male to female) and conversion to Islam.	No	The operation was prohibited.
2	1984 (Mar)	Sex change (female to male), conversion to Islam and marriage.	No	Doubt on maleness. The operation was prohibited. The conversion to Islam was accepted according to the initial gender. The marriage should be dissolved.
3	1989	Sex change and conversion to Islam.	No	Doubt on the new assigned gender. The operation was prohibited. The conversion to Islam was accepted according to the initial gender.
4	1993 (Feb)	Sex change and marriage.	*Khunthā*	Based on Ahmad Sharbasi's opinion, the reassigned gender should be accepted if it is dominant by eliminating the obscurity. The confirmation of the reassigned gender was handed over to Registry of Muslim Marriages.
5	1995 (July)	Role of authority on bathing ritual for corpse of a transsexual.	No	Person to perform ritual bath is to follow the sex at birth. In case there is no person with the same sex who would like to carry out the duty, the deceased's family is highly recommended to manage the body.

6	1995 (Nov)	Response on al-Azhar, Egypt's fatwa on issue of sex change.	Not applicable	Clarifying further the fatwa al-Azhar to reduce the confusion of public.
7	1997 (May)	Sex change and marriage.	*Khunthā*	The sex reassignment and the application for marriage was accepted.
8	2000	Prenatal sex assignment.	Not applicable	The effort of sex selection is allowed as it does not overrule Allah's predestine.
9	2005	Role of authority on handling marriage of a transsexual (Muslim and non-Muslim).	No	Muslim officers are not allowed to manage marriage of transsexuals.

The same role was played by the Council of Indonesian Scholars The first fatwa was issued on 1 June 1980. The fatwa highlights the prohibition of the surgery for those who would like to change their gender, because the action is incongruous with the Qurʾān, Ḥadīth and spirit of the sharīʿah. The reason for the undesirability of gender change is a refutation of Allah's predestined guidance:

> "…If you take a dislike to them it may be that you dislike a thing and God brings about through it a great deal of good."[760]

In contrast, the surgery is permissible for *khunthā* in order to confirm the masculinity of a man. Hence, the juridical rulings for the latter are based on the post-operation sex and the former group remain according the sex assigned at birth.[761]

The second fatwa was to empower the first by giving a detailed explanation 30 years later. In 2010, the Fatwa Committee decided to issue a fatwa on sex change and sex recuperation, following a number of cases of sex changes and judicial confirmations thereafter. The fatwa stresses that any act of sex change without valid evidence is prohibited. Thus, supporting a sex change or validating the operation is prohibited. The religious legal rulings remain according to the assigned sex at birth, even if permission for a sex change is acquired from the court.[762]

[760] Translation of the Qurʾān in ʿAbdullah Yūsuf ʿAlī, *Sūrah al-Nisāʾ* (The Women), 4: 19.
[761] Majelis Ulama Indonesia, p. 605.
[762] Majelis Ulama Indonesia, p. 605.

On the other hand, sex recuperation or corrective surgery is allowed for *khunthā*. Any act of supporting and assisting the operation is also permissible, with a condition that the justification is based on medical consideration and not be constructed on psychological factors. If sex reassignment occurs, the religious legal rulings are based on the new assigned sex, even before the courts confirm the sex change.[763]

7.5.2. Providing Necessary Advice and Guidance

The second role of religious leaders is providing necessary advice and guidance to the patients and the doctors. This role is played by the It is important to help and advice patients regarding their performance of religious obligations, particularly those related to gender. Zainuddin mentioned that:

> "For instance, a Congenital Adrenal Hyperplasia (CAH)-patient regards herself as female and everybody knows her as female, there is no problem about that and she can continue to be a girl. But very few among them who could not decide in which lane they are, in performing their (congregational) prayers (whether at female or male group)."[764]

As mentioned in the previous chapters, *khunthā* is subject to specific rulings as long as gender is not determined.[765] Therefore, continuous support for them is required to ensure they can fulfil their religious obligations as dutiful Muslims. Similar guidance is expected for parents as well, in order to bring up the affected children as any others. Even the children are bound with imperfect executive capacity, in which they are not obliged to carry out worshipping duties (*ʿibādah khuṣūṣiyyah*), performing such obligations are recommended as a training for them prior to reaching puberty. Hence, guidance on how such obligations should be performed is necessary.

Secondly, the role of religious authority is expected to ensure that the medical intervention, if any, is carried out according to the Islamic perspective. Jalaludin argued:

> "I would know the chemical perspective, like hormonal responses but from the Islamic perspective (the question is) whether we can or cannot (carry out a gender reassignment)? We want our decision to be in line with the Islamic rulings without any contradictions. If there are contradictions, we want to be

[763] Majelis Ulama Indonesia, p. 605.
[764] Ani Amelia Zainuddin, *Skype Conversation with Taqwa Zabidi*.
[765] See further explanation in Appendix C.

> able to come to a middle ground to treat the patient. We don't want to get over-excited about prescribing anything (treatments)."[766]

Similar opinion is observed from an Islamic scholar's response. Syed Sikandar Shah Haneef highlights the roles of religious leaders are expected for two reasons, i.e. to 'advise them (doctors) against slippery slopes (of moving from Islamic practice) and to appreciate that conventional wisdom of classical procedure of distinguishing true intersex from false ones to avoid juristic paradoxes.'[767]

This practice has been recognised in Indonesia. Ministry of Health of Indonesia referred to the Council of Indonesian Scholars with regard to sex assignment surgery. The extent to which their role is to explain the fatwas provided is not known. In contrast, there was no reference being made from the hospitals pertaining to medical intervention for patients with DSD in Singapore, as reported by the Mufti.

7.5.3. Confirmation on Gender Status for Management Procedures

The third role is related to confirmation on gender status for administrative purpose. As we can see, Mufti's decision is requested to ease registration process of marriage and conversion to Islam in Singapore as presented in previous subtopic. Similarly, in Malaysia, Islamic authority's decision is called for the confirmation of sex change process in the Identification Card, if sex reassignment does occur. While the documents from a religious body are not legally required by the National Registry Department, they will ease the process. In addition, the gender status is important because most of administrative processes will be referred to this citizen card. For instance, in school registration, working application, access to health facilities, registration of marriage, managing and dividing inheritance and even for procedure of criminal sentences.

These roles are played by religious leaders, either in juristic councils or departments of religious affairs that could be carried out as members of MDT or within their own capabilities. For the purpose of regulating fatwas, this role is played outside the MDT's

[766] Yazid Jalaludin, *Telephone Conversation with Taqwa Zabidi* (17 September 2016).
[767] Sayed S. Haneef, *Email to Taqwa Zabidi* (28 May 2016).

table of discussion. It is because a juristic council composed of its own members such as *mujtahidūn,* jurists who are not yet reach to the level of *mujtahidūn* and researchers in Islamic studies. However, more often than not, professionals of related issues are invited as non-permanent members. For example, the Council of Indonesian Scholars (MUI) plays its role in issuing a religious verdict or fatwa on gender ambiguity. Each verdict is submitted to the Ministry of Health in order that they may take any possible medical intervention for related patients according to their biological or psychological needs.

In playing their second role to provide advice and guidance for the patients or citizen at large, an institution overseen by Ministry of Religious Affairs, Indonesia, namely *Bimbingan Masyarakat Islam* (BIMAS – Guidance for Muslim Society) has extensive experiences in handling such cases even though DSD is unusual to them. H. Ismail Sulaiman, Head of Islamic Education and Development Division, BIMAS Islam affirmed that:

> "We have discussed about (the condition of) gay from Islamic point of views and provided support (for them) through BP4. We, in the Ministry of Religious Affairs play our roles in providing guidance and advice on such circumstances. However, we have not went through cases on hermaphrodite (or DSDs). This is new to us. We only manage cases on transvestite and gay for the time being."[768]

This institution actively performs their functions without having been members of MDT in managing patients with DSD.

In contrast, Malaysia experienced differently in giving advice to the doctors. The involvement of religious leaders in MDT contributes to ease the process of decision making. Jalaludin expressed his experience of consulting JAKIM on one of the DSD cases that having the representative in the MDT is vital. He stated:

> "I prefer that approach, instead of having to bring the case to JAKIM without anyone else providing an Islamic opinion before being taken to JAKIM. When I raise the case … at least I already have someone from JAKIM to meet with the patient and his/her family."[769]

[768] H. Ismail Sulaiman, *Conversation with Taqwa Zabidi* (26 September 2017).
[769] Yazid Jalaludin, *Telephone Conversation with Taqwa Zabidi*.

Participation in the early process of discussion will empower understanding on types of DSD and how *dis-order* occurs. This will enlighten the Islamic authorities in making later informed decisions, when performing their third role in supporting the application for sex change for Muslim patients. In the case of AA, the doctors and Islamic authorities made a joint statement which was forwarded to Department of National Registry for changing the sex status on the identification card. It shortened the easing the bureaucratic process considerably.

7.6. Challenges

The idea to include Islamic scholars in the MDT has been welcomed by the Mufti of Federal Territories, Zulkifli al-Bakri.[770] He is of the opinion that the involvement of Islamic scholars is highly recommended as mentioned in the Qurʾān: "If you realise this not, ask those who possesses the Message."[771] Mohd Izhar Arif Mohd Kashim and Islamic expert 2 pointed out that the combination of both parties (medical and religious) in the team will provide an accurate and clear decision for the patients and will avoid a misleading decision that could cause harm to patients. [772] A MDT that includes religious experts will safeguard the interests of both Muslim patients and their families.[773] As pointed out in the previous subtopic, the roles of religious leaders are significant. However, a question on whether those roles make them eligible to be involved in the Multi-Disciplinary Team (MDT) in managing patients with DSD remained unanswered. Several challenges were identified in terms of whether they are necessary to involve in the MDT. They include legal jurisdiction and separation of power, socio-political background, knowledge and awareness, help-seeking behaviour and credibility.

7.6.1. Legal Jurisdiction and Separation of Power

One of the challenges of the religious leaders' involvement in the MDT is pertaining to legal jurisdiction and separation of power of related institutions. In all three countries,

[770] Zulkifli Mohamad Al-Bakri, *Email to Taqwa Zabidi,* (25 March 2016).
[771] Translation of the Qurʾān in ʿAbdullah Yūsuf ʿAlī, *Sūrah al-Anbiyāʾ* (The Prophets), 21: 7.
[772] Mohd Kashim, Mohd Izhar Ariff, *Telephone Conversation with Taqwa Zabidi,* (13 January 2016); Islamic Expert 2, *Telephone Conversation with Taqwa Zabidi,* (21 January 2016).
[773] Islamic Expert 1, *Conversation with Taqwa Zabidi,* (27 August 2015).

there are established institutions that operate within their own legal jurisdictions as presented before. Healthcare and religious institutions are expected to exercise their power and complement each other. Currently, for policy makers such as the Ministry of Health, Malaysia, the Islamic Religious Council of Singapore and Ministry of Religious Affairs, Indonesia, there is no imperative factor that requires them to be in the MDT. The separation of power enables them to perform their jurisdictions and they deliver their services through effective communications between related parties.

In Malaysia, the management of DSD is mentioned in *Paediatric Protocols for Hospitals in Malaysia*. Within this protocol, the MDT will include paediatric subspecialists in endocrinology, surgery, and/or urology, psychology/psychiatry, gynaecology, genetics, neonatology, and social work, nursing and medical ethics.[774] Further explanation was obtained from Farida Abu Bakar, the Deputy Director, Division of Family Health Development, Ministry of Health (MOH). In an interview, she said:

> "If there is any conflicting procedures or decisions on religious or cultural aspects, the Ministry of Health will inquire opinions from the authoritative body such as JAKIM. The decision made will be the basis for MOH in developing any policies later, for instance, in the case of gender ambiguity."[775]

However, this does not enable the religious authority to be part of the Multidisciplinary Team members. She opined that:

> "Currently, the involvement of religious leaders in managing patients with DSD is not pressing because sex assignment of male and female is through the tests of chromosomal sex, reproductive system (including the gonads, internal and external organs) and secondary sexual characteristics. Besides, the available fatwas are clear to support further medical intervention. Yet, this is a good idea that we can consider in building up the long-term policy."[776]

She also highlighted that doctors could consider their religious beliefs in making such decisions as well as by referring to the fatwas that have been provided by JAKIM.

However, different views were obtained from other medical experts in the field of DSD. As mentioned before, Zainuddin, a professor and paediatric consultant at the Hospital of the National University of Malaysia, has set up a Multidisciplinary Team including

[774] Hussain Imam Muhammad Ismail, Ng Hoong Phak and Terrence Thomas, *Paediatric Protocols for Malaysian Hospitals*, 3rd edn (Putrajaya: Kementerian Kesihatan Malaysia, 2013), p. 263.
[775] Faridah Abu Bakar, *Email to Taqwa Zabidi* (8 September 2016).
[776] Faridah Abu Bakar, *Email to Taqwa Zabidi* (8 September 2016).

various subspecialisations of medical experts, a representative of JAKIM and an Islamic scholar from the same university in her MDT.[777] Zainuddin mentioned in our interview, "The reason I establish this committee is to cater for the religious context."[778] Her argument is supported by other experts' opinions including those of Roziana Ariffin, Yazid Jalaludin, and Rahmah Rasat.[779]

In the same vein, Bakaram mentioned that the role of religious authorities in Singapore depends on the provision of law, specifically the AMLA. There is no clear provision for religious authorities to participate in the biomedical decision making process and thus it remains a purely medical investigation considering all available information as well as other new extra medical data that becomes available. Therefore, he argues:

> "If asked whether Fatwa Committee could engage in managing medical cases, I would say there is no legal provision for that jurisdiction and it depends on the medical practitioners, hospitals or Ministry of Health to request for our assistance. If not, it will go back to the individuals who are facing such condition to request for our opinion. It will then be a feedback for the request and there is no legal binding on the statement issued."[780]

The roles of the Islamic authority seem unsought by the patients, their families or the doctors. It would therefore be unlikely for them to participate in the decision making process due to legal constraint, unless their advice is specifically requested by the appropriate authorities such as the Ministry of Health or the Bioethics Advisory Committee (BAC).

The same situation was observed in 1970s. Singapore was known as one of the best countries that provides sex change operations. The treatment was subsidized by the government in 1973 and it is accepted by law to change one's gender on the Identity Card according to the reassigned gender, while maintaining the assigned gender at

[777] The Hospital of National University Malaysia is a tertiary hospital and is overseen by the Ministry of Education instead of MOH. Therefore, it is not bonded with the regulations produced by the MOH, but by applying the rules, the standard of procedures is guaranteed.

[778] Ani Amelia Zainuddin, *Skype Conversation with Taqwa Zabidi* (20 July 2016).

[779] Roziana Ariffin, *Email to Taqwa Zabidi*, 9 September 2016; Yazid Jalaludin, *Telephone Conversation with Taqwa Zabidi* (17 September 2016); Rahmah Rasat, *Telephone Conversation with Taqwa Zabidi* (1 August 2016). Roziana Ariffin is a Consultant Clinical Cytogeneticist and Head of the Genetics Laboratory Kuala Lumpur Hospital; Yazid Jalaludin is a Consultant Paediatrician and Paediatric Endocrinologist at University Malaya Medical Centre; and Rahmah Rasat, is a Paediatric Endocrinologist at the National University of Malaysia.

[780] Fatris Bakaram, *Conversation with Taqwa Zabidi*.

birth on the birth certificate.[781] The first surgical treatment took place in 1971, five years after independence. Singapore was the first Asian country to conduct a sex change operation, led by S. Shan Ratnam (d. 2001), a Professor Emeritus and Head of Department of Obstetrics and Gynaecology at the National University Hospital, Singapore.

Treatments were conducted at Kandang Kerbau Hospital (now known as KK Women's and Children's Hospital), until Ratnam established the Gender Identity Clinic and the Gender Reassignment Surgery Clinic at the National University Hospital in 1975. Singapore celebrated having the top reputation of Sex Reassignment Surgery (SRS) during Ratnam's tenure leading these clinics. Half of the 500 operations were conducted on foreigners.[782] With these technological advances, numerous sex change operations had been done, yet little connection has been made with the management of DSD, whose patients might need to go through sex reassignment surgery, is known among MUIS members. Perhaps, as reported by the Mufti, lack of reference made by the individuals or hospitals contributes to the stagnant knowledge of *khunūthah* in its classical form.

Sex reassignment surgery was performed prior to 1971 for hermaphrodites. However, on 29 July 1971, a 24-year-old Chinese Singaporean underwent surgical intervention to change from male to female. It was recorded as the first of its kind aimed at 'functionally changing a person's sex and appearance'.[783] It caused public uproar as to what extent sex assignment surgery could be conducted. On 24 October 1972, the sixth patient was recorded as a Malaysian and believed to be a non-Muslim patient.

This service seems to be a desirable in East Asia among those who face gender dysphoria. Little is known about whether they had any types of DSDs. After the second operation, the hospital received 15 applications from neighbouring countries, including Malaysia, Thailand and Indonesia. Prior to treatment, all patients were asked to

[781] Audrey Yue, 'Trans-Singapore: Some Notes Towards Queer Asia as Method', *Inter-Asia Cultural Studies,* 18 (2017), p. 13.

[782] Chan Meng Choo, *First Sex Reassignment Surgery*, Singapore Inforpedia, (Singapore: Singapore Library Board) <http://eresources.nlb.gov.sg/infopedia/articles/SIP_1828_2011-08-04.html> [accessed 18 February 2019], para 9 of 10.

[783] Joseph Yeo, 'First Sex Change Surgery in Singapore', *The Straits Times,* 31 July 1971, p. 17; Chan Meng Choo, *First Sex Reassignment Surgery*, para 1 of 10.

undergo psychological investigation to confirm their transsexual status.[784] Post-surgical follow-ups were also scheduled to analyse patient status. Some of the patients publicised their life histories in the media.[785]

Syed Isa Sumait, the second Singaporean Mufti, published a statement on the front page of a mainstream newspaper on 28 February 1974.[786] He stated that sex change is accursed by Allah and thus is highly prohibited in Islam. He commented on this biomedical advance even though there were no Muslim patients requesting the surgery at that particular time. Meanwhile, in Malaysia, the Mufti of the Federal Territories (one of the states) was reluctant to issue any statement unless requested by the appropriate authority such as the Ministry of Health, due to his concern that his statement could have legal implications prior to proper investigation.[787]

However, eight months later, the first Malay Malaysian went through sex reassignment surgery in Singapore. Malaysians were shocked with the story of Mohd Fauzi bin Abdul Karim (later known as Sari Kartina), who transitioned from male to female. The surgery was conducted by Ratnam at Kandang Kerbau Hospital, Singapore on 24 October 1974.[788] Her story was disclosed by the media with the title 'Marriage after Sex Change' a year later. Kartina married Abdul Razak Othman in front of the Deputy Mufti of Johore State, Syed Alwee bin Abdullah at his office. There was no fatwa or statement provided by the Office of the Mufti with regard to this case, whether to advise the patient or the hospital pertaining to the Islamic rulings. Perhaps, this was due to the case being of a Malaysian patient and therefore out of the jurisdiction of the Office by law. The history indicates that every institution played their roles, but separation of power led to working in silos. Hence, the management of Muslim patients with gender ambiguity was not wholly administered effectively.

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[784] 'Pembedahan Jantina Kali Keenam Di-Kandang Kerbau (the Sixth Sex Surgery at Kandang Kerbau)', *Berita Harian,* 31 October 1972, p. 10 [accessed 9 November 2015].

[785] Examples of publicised stories can be found in 'Gembira Yang Paling Istimewa Bagi Shauna (The Most Exciting Moment for Shauna)', *Berita Harian,* 3 September 1979, p. 8; Guntor Sadali, 'Kahwin Lepas Tukar Seks (Marriage After Sex Change)', *Berita Harian,* 7 November 1975, Front Page, p. 1.

[786] 'Putusan Mufti: Tukar Jantina Haram (Mufti's Statement: Sex Change is Prohibited)', *Berita Harian,* 28 February 1974, p. 1.

[787] 'Mufti Malaysia Belum Sedia Beri Fatwa (Malaysian Mufti is Not Ready to Issue a Fatwa)', *Berita Harian,* 1 March 1974, p. 1.

[788] Guntor Sadali, 'Kahwin Lepas Tukar Seks' (Marriage after Sex Change), Berita Harian, 7 November 1975, p. 1.

Similar circumstances have been observed in Indonesia. Medical interventions rely solely on the recommendations of doctors. There are four main agencies responsible for managing issues related to gender ambiguity among Muslim citizens in Indonesia. The Council of Indonesian Scholars (MUI) plays its role in issuing a religious verdict or fatwa on gender ambiguity. The verdict is submitted to the Ministry of Health in order that they may take any possible medical intervention for related patients according to their biological or psychological needs. The Home Ministry and Ministry of Religious Affairs are responsible for post intervention programmes such as providing any required support and guidance for all patients according to their race and religion. Guidance for Muslim Society (*Bimbingan Masyarakat* – BIMAS Islam), an institution under the supervision of the Religious Ministry is responsible for formulating and implementing policies and technical standardization for Muslim society on Islamic affairs such as almsgiving and other matters. They also is responsible for giving support and advice following the treatment. Matters on marriage are overseen and administered by the Institution of Advisory, Development and Preservation of Marriage (*Badan Penasihatan dan Pelaksanaan Pelastarian Perkahwinan* - BP4). There is no further need for Islamic authorities to play a role thereafter, unless there is any dispute pertaining to the status of sex which requires a court decision.

7.6.2. Socio-political Background

In the case of Singapore, the socio-political pattern of Islamic administration is a contributing factor to the adverse response towards Islamic authorities' participation in the MDT. It is because Singapore practices secular governance that separate religious matters and state policies. This is not absolute secularism, rather as Walid Jumblatt Abdullah argues, it is *muscular secularism* in which there is a direct, interventionist approach characterized by draconian measures, harsh laws, and formal co-optation.[789] MUIS agrees for co-optation with the state for certain reasons and the state also benefits from this type of relationship in order to mitigate conflicts between

[789] Walid Jumblatt Abdullah, 'Religious Representation in Secular Singapore: A Case Study of MUIS and Pergas', *Asian Survey*, 53 (6)(2013), 1182-1204, p. 1183.

Muslim minority communities and the state.[790] The state benefits from the co-optation to legitimate its own authority and to facilitate Muslims' affairs through religious knowledge and facility. In addition, with MUIS as the arm of government, issues like religious extremism could be curtailed. MUIS as a statutory body gets sufficient funding from the government for development of religious infrastructure. Additionally, MUIS also can give advice to the state in some areas and influence the state's decision.

However, as stipulated in AMLA MUIS and the Office of the Mufti limit themselves to engage closely with the authoritative medical practitioners in managing Muslim patients with DSD or in other words, in cases of gender ambiguity. Additionally, the administrative process of sex reassignment does not require any support from an Islamic authority. Individuals may change their sex based on the recommendations of their doctors.

Unlike Singapore, Malaysia and Indonesia enjoy a certain degree of cooperation between religious institutions and healthcare authorities. This is due to the fact that Islam is upheld as national religion and Muslims are the majority of citizens. Hence, the awareness of the rights of Muslims is considerable. In this case, Malaysia recognises Islam as the religion of the Federation, it facilitates the management of Muslim patients in a better way. Although the Ministry of Health is of the opinion that the participation of Islamic authority in the MDT is not vital, the Ministry acknowledges their roles, as stated in its current publication:

> "Inform parents/guardians that the treatment include various experts such as geneticist, psychiatrist, psychologist, religious authority, welfare department and others as required."[791]

At least, the separation of power as the aforementioned just need better collaboration between the authorities to ensure a better quality of life for the patients, carrying out medical intervention from Islamic perspectives and supporting them in the

[790] The state benefits from the co-optation to legitimate its own authority and to facilitate Muslims' affairs through religious knowledge and facility. Having MUIS as the arm of government, issues like religious extremism could be curtailed. On the other hand, MUIS as a statutory body holds sufficient funding from the government for development of religious infrastructures. In addition, MUIS also can gives advises to the state and influence the state's decision.

[791] Division of Family Health Development, *Garis Panduan Pengendalian Masalah Kesihatan Gender Di Klinik Kesihatan (Guidelines of Management of Gender Disorder at Health Facilities)*, ed. by Faridah Abu Bakar, Zakiah Mohd Said and Jamal Abdul Nasir (Putrajaya: Ministry of Health, 2017), p. 14.

administrative requirements of sex change registration if required. ‘Both the religious authorities and medical experts need to cooperate with and educate each other about the various aspects of care of the patient with a DSD’.[792]

7.6.3. Knowledge and Awareness

The most challenging factor is knowledge and awareness with regard to DSD, its types and its relationship with *khunūthah*. A lack of knowledge might have an adverse effect on how such cases are managed. Wrong decision may cause untreated cases, mistreatment or negative implication following the decision made due to lack of knowledge. For instance, there was a case reported in Malacca, a state of Malaysia. Spouses were ordered to divorce by a court due to same-sex marriage. The investigation revealed that the marriage had been conducted according to Islamic law. However, the root of problem was identified a couple of years earlier, when a religious officer simply acknowledged the statement of the ‘groom’ being male at a later age without detailed diagnosis and treatment. The written acknowledgement was used by the 'groom’ as a recommendation for sex change from female to male at Registry Department, which led to the consent of marriage registration. This would not happen if this case was managed by Multi-Disciplinary Team, or was at least referred this case to appropriate doctor. [793]

Understanding of the condition has been gradually developed in Malaysia particularly at federal level. The awareness of Muslim doctors to seek religious perspectives demands religious authorities to equip themselves with understanding of this rare condition. This is shown by the role of the Ministry of Health in notifying the Fatwa Committee of current conditions and terminologies, and by those doctors who forwarded the individual cases to JAKIM. However, little is known about whether religious officers at the state level have a similar exposure to DSD. The separation of power at federal and state levels in bioethical issues is not elusive as they can forward

[792] Ani Amelia Zainuddin and Zaleha Abdullah Mahdy, 'The Islamic Perspectives of Gender-Related Issues in the Management of Patients with Disorders of Sex Development', *Archives of Sexual Behavior*, (21 April 2016), 7.

such cases to JAKIM. Still, their expertise is required to cater any problem which may occur in the states.

Meanwhile, DSD is unfamiliar among members of Islamic Religious Council of Singapore (MUIS). Former Mufti of Singapore remarked, even if the scope is narrowed down to *khunthā*, it will never be a polemic in the country. He reiterated his opinion on DSDs or *khunthā* as follows:

> "Since 1993, I have been working until currently, *khunthā* is not something that is attractive to people neither among Muslims, nor among non-Muslims."
>
> "For issue on *khunthā mushkil*, it never be queried by the public or individuals, that require Fatwa Committee to explore further (on the issue)… such as on genetic disorder, chromosomes and others."
>
> "I would say that issue on *khunthā* does not bother the public. Those who are facing this condition never come and ask for guidance individually. To date, there is no single person come to ask further on it. Therefore, we still hold on the most traditional definition based on the classical *fiqh*."
>
> "If you ask is there any religious consideration in biomedical ethics in Singapore, the answer is yes. But not on *khunthā mushkil*. It never been highlighted."
>
> "Yes, it is not widely discussed among public and there is no economic value."
>
> "… There is no any movement that shows it is a problem faced by any individuals."[794]

Like in Singapore, Islamic authorities in Indonesia show little awareness of DSD. *Khunthā* is understood in its classical context and has never been discussed in relation to the advanced medical findings on DSD. Currently, focus is given to the cases of gender dysphoria including those in the Lesbian, Gay, Bisexual and Transgender (LGBT) group. The Ministry of Religious Affairs acknowledges recognition of this group by other countries. However, the Ministry stands for 'rejection of the LGBT's sexual behaviour and same sex marriage'.[795] As such, the Ministry regulates plans of action in order to embolden family institutions through pre-marital courses and empowering

[794] Fatris Bakaram, *Conversation with Taqwa Zabidi* (23 March 2017).

[795] BIMAS Islam, 'Sesuai Konstitusi, Menag Tegaskan Nikah Sejenis Tidak Akan Dilayani (as Per Constitution, Same Sex Marriage Will be Unrecognised)', *Bulletin BIMAS Islam,* XXXVII (2016), p. 3.

Institution of Advisory, Development and Preservation of Marriage and other religious organizations by providing correct understanding of LGBT and the way to curb an inverse culture from becoming widespread among the communities. In an interview conducted with H. Ismail Sulaiman, Head of Islamic Education and Development Division, BIMAS Islam, he affirmed that:

> "We have discussed about (the condition of) gay from Islamic point of views and provided support (for them) through BP4. We, in the Ministry of Religious Affairs play our roles in providing guidance and advice on such circumstances. However, we have not went through cases on hermaphrodite (or DSDs). This is new to us. We only manage cases on transvestite and gay for the time being."[796]

However, the researcher determined that there are misconceptions pertaining to the terms used. The Minister of Religious Affairs, Lukman Hakim Saifuddin once mentioned that:

> "Indonesia chooses its own stand to disapprove LGB and to apprehend the transgender. This refers to World Health Organisation's (WHO) recommendation for every country to hold on its own approach and policies depending on the values and local wisdom."[797]

He continued that there is general simplification of the use of the terms among society whenever all LGBT are banned for religious reasons. Relying on 'Islamic perspectives', he said that LGB behaviour is condemned due to its immoral sexual orientation. However, the sanction is inappropriate for 'T' or transgender because this group is identified as *khunthā* in Islam, for which different rulings are applied. The question here is: Is transgender *khunthā*?

As we have explored in Chapter 3, there are differences between transgender, *khunthā* and DSD. These terms could not be used interchangeably in general, as they have different meanings and characteristics. Misunderstanding could be perilous to Islamic understanding and practice; and even to society as a whole. Associating transgender in its local context to *khunūthah* which is DSD will only lead to psychological and social difficulties. Transgender is closely related to *waria, banci* or *wadam* (Indonesian terms for male transvestite) and *bencong* or *wandu* (Indonesian terms for female transvestites). These are ostracising and disrespectful terms.

[796] H. Ismail Sulaiman, *Conversation with Taqwa Zabidi* (26 September 2017).
[797] BIMAS Islam, p. 3.

Individuals with DSDs and *khunūthah* are affected negatively by association with these terms in a way that causes them suffer from stressful conditions due to social stigmatization. Hence hesitation of acquiring experts' opinions and proper treatments can be traumatic. The impact is higher on individuals whose surrounding is a 'collective-driven' society such as in Indonesia.[798]

Sulaiman also opined that:

> "There are *khunthā* cases in Indonesia. But they are not disclosed to the media or to the society revealing that one of the family members is a *khunthā*. The individual will act towards male or female, and would never expose to the internet or newspaper disclosing the condition... He or she might feel ashamed to inform the gender status either as a man or a woman… Only at later age, when decision is made, then he or she will publicly inform (the gender status)."[799]

This scenario indicates that complete understanding of DSD and *khunūthah* is important. Lack of knowledge will lead to many difficulties in managing patients with DSD. Additionally, poor awareness might lead to less concern being placed on the importance of being involved in the MDT.

7.6.4. Help-Seeking Behaviour

The involvement of religious scholars in the Multidisciplinary Team (MDT) is welcomed by medical teams in Malaysia for additional support in order to ensure that the patients are able to sustain a better quality of life after treatment. While imams or Islamic scholars become the reference in most health and medical issues, the trend of help-seeking behaviour of patients with DSDs in Southeast Asian countries varies. Based on the interviews, it is assumed that there is a lack of referred cases, by the patients and families, to the Islamic authorities particularly on sex assignment and its treatment. In Malaysia, it was the doctors who requested further clarification from the Islamic perspectives, with the permission of the patients. In addition, fatwas were sought for post-operation implications such as status of marriage, religious conversion and sex status on the Identification Card.

[798] Annastasia Ediati, Nani Maharani and Agustini Utari, 'Sociocultural Aspects of Disorders of Sex Development', *Birth Defects Research Part C, Embryo Today, Reviews*, 108 (2016), p. 381.
[799] H. Ismail Sulaiman, *Conversation with Taqwa Zabidi.*

As mentioned before, the roles of the Islamic authority seem unsought by the patients, their families or the doctors. It is awkward to discuss gender ambiguity, especially in society that considers this topic as taboo.[800] In Indonesia, patients are expected to experience the same social difficulties as the transgender groups go through. They will find difficulties in using their Identification Card (*kartu identitas*) especially in applying for marriage, accessing benefits provided by the government to the public, as well as in their professional careers.[801] This is obviously worse for individuals with DSD, whose gender is inconsistent with the assigned sex at birth. The reason is the individual's sex is printed on the card and should be consistent with the birth certificate. While the information is indisputable, the physical appearance may indicate the other gender.

A study was conducted to analyse social stigmatisation faced by late identified Indonesian patients with DSDs[802]. The respondents were 34 adult patients and 81 parents of children and adolescents with DSDs. The majority of them were Muslims. The results indicated that the stigmatisation was highly observed among patients who could not conceal their ambiguity (physical appearance and cross gender behaviour roles); in untreated patients; in those who changed their gender; and in girls and women. A number of patients were found who withdrew themselves from social interactions such as missing school and avoiding any conversation with neighbours. One of the reasons for this problem is a lack of knowledge about DSDs among the patients, the affected families and society.

The situation of fear and isolation leads to a lack of help-seeking behaviour among affected individuals and families. There is a lack of evidence to show that the attitude of reticence in patients contributes to the lack of awareness among non-medical authoritative personnel in the management of patients with DSDs. However, it is strongly assumed that the cycle of this problematic situation will continue to surround

[800] Annastasia Ediati, Nani Maharani and Agustini Utari, Sociocultural Aspect of Disorders of Sex Development, p. 381.

[801] Siti Kurnia Widiastuti, Farsijana Adeney Risakotta and Siti Syamsiyatun, 'Problem-Problem Minoritas Trasngender Dalam Kehidupan Sosial Beragama (Problems that Minority Group of Transgender Facing in Religious Social Life)', *Jurnal Ilmiah Sosiologi Agama Dan Perubahan Sosial*, 10 (2016), 92.

[802] Anastasia Ediati and others, 'Social Stigmatisation in Late Identified Patients with Disorders of Sex Development in Indonesia', *BMJ Paediatrics Open,* (2017), 1 – 9, p. 4.

the healthcare providers, the patients and the families if the authoritative bodies and communities are not nurtured with the knowledge of DSDs from medical and Islamic perspectives.

The apparent reluctance of patients to seek Islamic clarification regarding their DSD, partially explain why DSD and its variations are uncommon among Islamic authorities in Singapore and Indonesia. In fact, to those authorities, DSD itself is jargon that require further explanation. Consequently, DSDs or *khunūthah* does not seem important to be discussed and managed by the authorities. The classical notion of *khunūthah* is accepted as it is, without further exploration and synchronization with current medical findings. On the other hand, the authorities focus more on the issue of LGBT among Muslim communities, and yet there is a thin line between the conditions of gender dysphoria and DSD. Therefore, in Singapore and Indonesia the participation of Islamic authorities in the MDT is undesirable. The available fatwas appear to be sufficient to help the medical team to understand the Islamic guidelines and act accordingly.

7.6.5. Credibility

As presented in Chapter 6, respondents suggested for religious leaders' role in decision making process. The respondents among Islamic scholars believed their role is important to verify medical recommendation made by the doctors. However, that does not clarify whether they need to be in the MDT or playing their role separately. Responding to this issue, one Mufti of Pahang State, Abdul Rahman Osman, strongly argued for consultation with the authoritative body, instead of having an Islamic representative in the MDT. According to him, it is good to have a representative in the MDT and he/she should be a competent religious leader due to the existence of different schools of thought and diversity of opinions. A scholar would ensure the credibility of the decision as what is practiced in Malaysia pertaining to the issuance of halal certificate for food and consumer goods. The technical committee works within its own expertise, and later the decision is forwarded to the 'Halal Committee' for further analysis from the Islamic perspectives.[803]

[803] Abdul Rahman Osman, *Telephone Communication with Taqwa Zabidi.*

It shows that the decision made by the MDT is not absolute. It is because the participation of a single Islamic scholar in the team does not always demonstrate the decision of an authoritative body. He based his argument on a verse from the Qurʾān as follows:

> "O ye who believe! Obey God, and obey the Messenger and those charged with authority among you."[804]

'Those charged with authority among you' are the Islamic Council or fatwa committee, according to Osman.[805] Therefore, it is important to forward such cases to the authoritative body even if it has been discussed in the MDT. The decision made collectively is more reliable compared to single opinion as discussed earlier. In this sense, Jalaludin suggested that the representative could help the MDT to identify sharīʿah issue, clarify any related fatwas, direct the decision making in conformity with sharīʿah. When the MDT's decision is forwarded to the authoritative body, it would help them to understand the issue and assist them to verify the recommendation and definitely provide any supporting mechanism ensuing the treatment. The only problem of double layer discussion is time consuming, whereas the patients and family always require urgent solutions.

7.7. Conclusion

The participation of religious leaders in the MDT caring for patients with DSD is welcomed by the medical practitioners in general. Their roles and contributions, as discussed in Chapter 6, are significant to ensure a good quality of life for the Muslim patients in terms of their religious conduct and to safeguard proper management of the patients according to the Islamic ethics and rulings. There are three main roles of Islamic authorities in dealing with cases of DSD, which are regulating fatwas, providing necessary advice and guidance and conforming gender status for administrative procedures. Whilst the first role is required to be performed outside the table of MDT's discussion, the second and the third roles would be played as members of MDT. Nonetheless, the involvement in the MDT depends on several challenges such as

[804] Translation of the Qurʾān in ʿAbdullah Yūsuf ʿAlī, *Sūrah al-Nisāʾ* (The Women), 4: 59.
[805] Abdul Rahman Osman, *Telephone Communication with Taqwa Zabidi*, (27 February 2016).

legal jurisdiction and separation of power, socio-political background, knowledge and awareness, help-seeking behaviour and credibility of representatives in the MDT.

However, the roles of authoritative organizations and Muslim scholars (referred to as the Muftis and the institutions of fatwa) depend primarily on the law of the land and the available administrative procedures as to what extend their contributions are required. Medical practitioners in Malaysia admit that religion does play its role in the management of the patients especially within the religiously-accentuated communities. Malaysia as an Islamic state faces fewer challenges regarding the participation of the religious leaders in the MDT. Their roles are beyond merely providing the fatwas. Their contributions are sought to assist the doctors in the decision-making process as well as in the administrative procedure of sex registration in the Registry Department. They are also expected to enhance the understanding of the public on the condition of DSD from the Islamic perspectives.

On the other hand, religious leaders in Singapore have more restricted jurisdiction in terms of their authority. Hence the probability of them participating in the MDT requires further justification. Though, it does not reduce their capability in managing patients with DSD out of the MDT's table of discussion. The expertise of religious authorities in guiding their patients and the families is perceived through the fatwas and other social supports and interactions. The model of the roles of Muslim chaplaincy in Muslim minority communities, such as in the United Kingdom, may contribute another perspective of how their roles are perceived and could be exercised.[806] In addition, knowledge and awareness among *ulu al-amr* and *'ulamā'* regarding this condition should be enhanced to ensure better management of patients with DSD.

Indonesia has a different situation given that the law of the land incorporates Islam as the religion of the nation. It has been proved that the contribution of the religious leaders is required in managing Muslim patients with DSD. However, it is suggested that further engagement of both parties medical and Islamic authorities should be encouraged in order to curtail any issues pertaining to ethical dilemmas faced by the

[806] See further details of Muslim Chaplaincy in Sophie Gilliat-Ray, Mansur Ali and Stephen Pattison, *Understanding Muslim Chaplaincy* (England: Ashgate, 2013).

patients and the affected families. Collaboration with Islamic authorities supports the medical team in ensuring a better quality of life for the patients, carrying out medical intervention from Islamic perspectives and supporting them in the administrative requirements of sex change registration if required. ‘Both the religious authorities and medical experts need to cooperate with and educate each other about the various aspects of care of the patient with a DSD’.[807]

[807] Ani Amelia Zainuddin and Zaleha Abdullah Mahdy, 'The Islamic Perspectives of Gender-Related Issues in the Management of Patients with Disorders of Sex Development', *Archives of Sexual Behavior*, (21 April 2016), 7.

8. CONCLUSION AND RECOMMENDATIONS:

Concerning the condition of Disorders of Sex Development (DSD) from an Islamic Perspective.

8.1. Conclusion

This multidisciplinary study was conducted to evaluate Sunni Islamic perspectives concerning a medical issue known as Disorders of Sex Development (DSD). This research sets out for the following objectives:

a. to evaluate the relationship between *khunūthah* (hermaphroditism) and associated gender assignment with the various types and complications of DSD the patient is faced with;
b. to identify the Islamic bioethical underpinnings for DSD conditions affecting gender assignment, treatment and the decision-making process;
c. to determine the need for the involvement of Muslim scholars in a multidisciplinary team to manage patients with DSD.

This in-depth qualitative study, by taking sharīʿah as the legal and ethical frameworks, indicates several important findings as follows.

Firstly, *khunūthah* as it is commonly understood refers to a condition of a person who cannot be recognized as male or female; and the person has both physical criteria for men and women. The classical delineation remained unchanged in nature. Whereas, biomedical studies appeared with a large amount of information on cases of abnormality in human biological development. Whilst the jurists emphasized on urine excretion (*al-mabāl*) as a means of gender assignment; physicians point out the role of chromosomes and gonads. *Khunūthah* should be redefined by associating the elements of ambiguous genitalia together with atypical chromosomes and gonads. Hence, *khunūthah* should be referred to as a congenital condition of uncommon presence of genitalia with the disjunction of chromosomal and/or gonadal sex. This redefinition will contribute to a better understanding of the term *khunūthah* and thereby be able to minimize bioethical conflicts.

Secondly, both Islamic and medical perspectives argue for subsuming *khunūthah* and DSD conditions under the dualism of male and female gender. However, there are

some similarities and differences between these two conditions that obstruct direct reference of *khunūthah* as a DSD or vice versa. There are slightly different forms in cases of ambiguity. When the presence of normal genitalia is incongruent with chromosomal and gonadal sex the condition is identified as DSD. Yet, *khunūthah* is identified through the presence of ambiguous genitalia.

Evidently, not all DSD can be referred to as *khunthā* but *khunthā* can be identified as a person with DSD. Any DSD types that retain normal male and female genitals are not regarded as *khunūthah* just as they are excluded from the category of intersex. Other types of DSD with genital ambiguity entail the condition of *khunthā.* The majority of ambiguous genitalia cases are regarded as *khunthā wāḍiḥ* (discernible *khunthā*) in which the 'correct' gender can be identified. As the technology develops and the knowledge expands, it will be possible to ascertain the gender of most *khunthā* cases, leaving only the very subtle abnormalities beyond the discernment capability of doctors. Those unrecognisable cases will retain the description of *khunthā mushkil* (intractable). This clarification is important as a person identified as *khunthā* is subject to the specific Islamic rulings in performing their religious duties and obligations.

Thirdly, by ascertaining the relationship between *khunūthah* and DSD, it shows that different rights and rules for *khunthā wāḍiḥ, khunthā mushkil* and other types of DSD can be applied separately, especially in terms of gender assignment and treatment as follows:

a. *Khunthā wāḍiḥ* (discernible *khunthā*)

   This group of persons is subject to *fiqh* of *khunūthah* until the dominant gender is ascertained. As soon as the gender is determined, the person is subject to the rules according to the assigned gender. Gender assignment is identified based on the 'Islamic biomedical approach' as has been recommended in Chapter 4. The treatment is required to obliterate ambiguity, and to restore physiological and psychological health. Hormonal treatment is prioritized, if available, over surgical treatment. Timing for surgical treatment, if necessary, should be based on the 'level of strength' of *maṣlaḥah* as explained in Chapter 5.

b. *Khunthā mushkil* (intractable *khunthā*)

This group of persons is subject to *fiqh* of *khunūthah* until the dominant gender is ascertained. Only then, will the person will be subject to the rules according to the assigned gender. Gender determination is perceived impossible for this group as the dominant sign is unclear. A physical evaluation could be carried out from time to time to observe if there are any biological or physical changes. Therefore, sex assignment surgery is unnecessary until the appropriate signs of sex prevail to ascertain the dominant gender. Other required treatment is to be conducted to restore physiological and psychological health.

c. Other types of DSD

This group of persons is subject to the rulings according to the assigned/reassigned gender. Thus, *fiqh* of *khunūthah* is not applicable in this case. Gender remains as what was assigned at birth unless gender reassginment is required. The 'Islamic biomedical approach' is used in reassignment cases for the correct-sex determination. All required treatment is to be conducted to restore physiological and psychological health. Patients should not be subject to the Sex Assignment Surgery (SAS). Timing for other surgical treatment, such as gonedectomy, if necessary, should be based on the 'level of strength' of *maṣlaḥah* (public interest).

Fourthly, the 'Islamic biomedical approach' is proposed for the gender assignment. This approach is to include altogether the following criteria:

a. The classical Islamic approach on the phenotype elements.
b. The biological model on the phenotype, genotype, chromosomal and gonadal factors.
c. The analysis of *maṣlaḥah* pertaining to the psychosocial wellbeing of the patients.

This strongly affirms the significance of the proposed redefined version of *khunūthah,* as to include the association of chromosomal and gonadal factors in the case of ambiguous genitalia.

Fifthly, from the Islamic perspective, treatment is permitted to restore one's health physiologically and psychologically. Muslim jurists have welcomed the advancement of biomedical technology to bring about better chances to identify and rectify ambiguous external genitalia. The deliberation encompasses the permissibility of a treatment with regard to the categories of *khunūthah* and DSD. *Maṣlaḥah* is proposed as a mechanistic tool to reflect on the current debates on the timing of surgical treatment for minor patients and can extend to all DSD patients at large.

The appropriate timing of elective or urgent surgeries is observed through preponderance technique (*tarjīḥ*) based on weighing the 'strength' and the 'implication' factors of *maṣlaḥah*. The urgent surgery is depicted through the level of 'necessary' in *maṣlaḥah* and thus should be conducted immediately. While the elective surgery is classed in the level of 'complimentary' or 'embellishment' according to its importance and therefore postponement of surgery is appropriate. The implication of the surgery should be taken into consideration as well. Analyses should be made of the surgical outcome and comparison should be made between early intervention and delayed intervention as well as the long-term results of non-operative intervention.

Sixthly, the decision making process is closely associated with the principle of autonomy of the patients to acquire their rights. Competency is viewed as the vehicle to be autonomous agents. Therefore, the focus has been given to the needs of the patients and the importance of respecting their decision. In contrast, Islamic ethics focuses on competency in performing one's duties. It implies that everyone who is attributed to the management of patients with DSD should carry out the duties within their own sphere. Explication of capacity also underlies the requirements of guardians over children and other persons with imperfect or deficient capacity. As every related party, who is *mukallaf* (capable) is subject to perform their duties, those responsibilities are expected to be performed even in the decision-making process. This concept is in harmony with the commandment of Allah in exercising consultation or *shūrā*.

However, both Islamic and medical perspectives call for mutual agreement in the decision-making process. Consultative autonomy could be applied through *shūrā* or what is termed in the medical setting as the shared decision-making model. This model

is illustrated in current practice of establishing Multidisciplinary Team (MDT) in managing patients with DSD.

Seventhly, religious authorities contribute important roles in the management of the patients. Previously, their roles were expected in the consultation pertaining to performance of religious matters such as marriage. Currently, their contributions can be seen through their provision of viable fatwas as guidance for the medical practitioners and public. Besides, based on scholars' authoritative jurisdictions, the religious authorities would help in the administrative process providing confirmation of the sex change status, if necessary. However, participation of religious authorities in the Multidisciplinary Team in managing patients with DSD depends on the law of the land and the available jurisdictions as to what extend their contributions are allowed. It is suggested that further engagement of both religious and medical authorities together, should be conducted in order to curtail any issues pertaining to ethical dilemmas and to create awareness of this condition so that the patients are encouraged to get the proper treatment.

Lastly, based on overall analysis, Islamic biomedical ethics that is profoundly established in the sharīʿah framework provides a holistic approach in analysing medical issues especially the condition of Disorders of Sex Development. The sharīʿah sources are immutable and its objectives are beyond worldly matters. Hence the sharīʿah provides a sustainable and flexible guideline that is applicable across time and geographical boundaries. Its universal character is adaptable within various backgrounds of cultures, policies, practices and values among Muslim societies. As a guidance, it is not only about obligatory (*wājib*) and forbidden (*ḥarām*) actions, but also about acts between them such as recommended (*mandūb*), discouraged (*makrūh*) and permitted (*mubāḥ*) categories.

8.2. Recommendations and the Way Forward

Based on this research, four recommendations are made as follows:

a. Active engagement of both medical and religious scholars are required to ensure better management of the patients with DSD. Exchanging of information

between both parties will help to reduce the ethical dilemmas faced by the patients, the affected families and the medical practitioners themselves.

b. Religious leaders, including muftis, imams and religious officers, are recommended to get involved in the management of the patients with DSD and explore deeply the medical context. If not already, they should make themselves acquainted with the cause of rulings or known as *taḥqīq al-manāṭ* in the principle of Islamic jurisprudence. Knowledge is important in order to avoid any unnecessary decisions especially throughout the consultation on decision-making and matters related to Islamic rulings.

c. A holistic guideline on the management of patients with DSD, by taking into account the Islamic perspective should be developed. This will help: i) the medical practitioners in providing for the patient, better recommendations of the gender assignment and the ensuing treatment; and ii) the religious leaders in delivering proper support for patients within their own capabilities and jurisdictions.

d. More information on this particular condition should be disseminated among the public so as to create awareness about the various condition of DSD, its relationship to *khunthā* and matters related to religious obligations and duties of the patients. On top of that, the information is to encourage the patients and the families to get the proper treatment at the earliest age or as soon as a problem is identified. The knowledge is also to help to reduce ignorance and intolerance among the public that results in patients suffering social stigmatization and to increase social support to the affected patients and their families.

It needs to be noted here that this study is a preliminary groundwork demonstrating how the theoretical Islamic principles used in a few specific cases can be extended to be applied more generally in the many varieties of DSD that appear. Although the points of view of experts were taken into consideration throughout this research, more data needs to be collected to fully understand the lived experiences of Muslim patients and families and the challenges that they face. Having the Islamic theological

perspective as its ground, further research based on an ethnographical aspect in other local and cultural contexts will deepen the understanding.

Besides, more data could be analysed on the physicians' understanding and their awareness on the available fatwas and their effectiveness in current practice. Similarly, other research could be conducted to view social awareness of the Islamic principles pertaining to the condition of DSD. The framework of Islamic biomedical ethics might also be examined in other medical conditions. Moving a bit further away from Islamic studies, this condition of DSD might be reviewed from other religious perspectives so as to enrich the discussion of DSD from different views.

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APPENDIX

Appendix A

Approval Letter from JAKIM

DIRECTOR GENERAL
DEPARTMENT OF ISLAMIC DEVELOPMENT MALAYSIA
IN THE PRIME MINISTER'S DEPARTMENT
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FEDERAL GOVERNMENT ADMINISTRATIVE CENTRE
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المدير العام
لمصلحة الشؤون الاسلامية الماليزية
برئاسة مجلس الوزراء
الدور 9 مبنى D7 منطقة D
المجمع الاداري للحكومة الفيدرالية
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Website : http://www.islam.gov.my : الموقع على الشبكة

Our Ref: JAKIM.KP.100-6/1 Jld. 3 (3)
Date : 9 March 2015

Mrs. Alison Sables
Senior Administrative Officer
Postgraduate Research Office
Lampeter Campus
SA48 7ED
United Kingdom

Dear Mrs. Alison Sables,

First and foremost, we are pleased and honoured to be informed that our staff, Taqwa binti Zabidi has been accepted to further her study in the University of Wales Trinity Saint David.

Referring to the Ethics Committee's concern on the research that will be conducted, we would like to confirm that Taqwa binti Zabidi is granted the access to the case studies that this department holds as well as other related data providing that she complies with all the University's rules and regulations in carrying out her research.

In our practice, any data which is recognized as classified document by this department should be kept accordingly as recorded in *Arahan Keselamatan* (Safety Instructions) and *Dasar Keselamatan ICT* (ICT Security Policy). In this instance, the researcher has to comply with the University's procedure, yet this department recommends that any classified data that will be collected for research purposes should be kept confidential, accurately recorded, protected with security code for electronic document and within considerable attention during data collection, data cleaning and dissemination.

We are highly confidence that this research through the University's supervision will benefit all related parties especially in Malaysia. Thank you.

Yours faithfully,

(DATO' OTHMAN BIN MUSTAPHA)

Appendix B

Notes on Islam and Medicine

Medicine, as a part of science, illustrates well the understanding of the relationship between Islam and science. The word *ṭibb* (medicine), an Arabic word, is never mentioned in the Qurʾān. But the relation between Islam and medicine is accessible throughout various aspects of human life in this Holy Book. Its content is replete with the precept of preserving human life and dignity regarding biological conditions, such as diet and hygiene, as well as life and death.[808] Further, it has also been emphasized in the Ḥadīth of the Prophet Muḥammad. Great efforts have been made by scholars who collected, compiled and categorized the *Aḥādith* (traditions, plural form of Ḥadith) into a volume known as *Kitāb al-Ṭibb* (Book of Medicine) from the four prominent books of compilation of Ḥadīth, known as *Ṣaḥīḥ al-Bukharī*, *Sunan al-Tirmizī*, *Sunan Abi Daud* and *Sunan Ibn Mājah*[809]. In *Ṣaḥīḥ Muslim*, *Aḥādith* related to medicine have been compiled in two different chapters, which are *Kitāb al-Ashribah* (Book of Drinks) and *Kitāb al-Salām* (Book of Salutation)[810]. Similarly, in *Muwaṭṭaʾ Mālik*, several *Ḥādith* have been compiled in different subtopics within *Kitāb al-Jāmiʿ* (General Book), namely *bāb al-ʿain wa al-maraḍ* (chapter of eyes and illness). In general, all of these *Aḥādith* indicate the principle of treating a disease, traditional pharmacology, i.e. using specific kinds of components such as herbs, honey, dates, black beans or milk to promote a cure, or of prohibition of using unlawful ingredients, spiritual medicine as well as ethics in treating and visiting a patient.[811] Some of these *Aḥādith* reflect

[808] See for example; i) the verse of the Qurʾān, *Sūrah al-Ḥajj* (The Pilgrimage), 22: 5 explaining human creation; ii) *Sūrah al-Baqarah* (The Heifer), 2: 168 recommending eating lawful and good dishes; iii) *Sūrah al-Tawbah* (The Repentance) 9: 108 reminding that Allah loves purity; iv) *Sūrah al-Aʿrāf* (The Heights), 7: 34 mentioning life and death.

[809] Muḥammad ibn Ismāʿil al-Bukhārī, *Ṣaḥīḥ Al-Bukhārī*, ed. by Abū Ṣuhayb al-Karamī (Saudi Arabia: Bayt al-Afkār al-Dawliyyah, 1998), pp. 1131 – 1160; Muḥammad ibn ʿIsā ibn Thawrah al-Tirmizī, *Al-Jāmiʿ Al-Mukhtaṣar Min Al-Sunan*, ed. by Farīq Bayt al-Afkār al-Dawliyyah (Saudi Arabia: Bayt al-Afkār al-Dawliyyah, 1999); Abu Daud Sulayman ibn al-Ashʿath al-Sajistānī, *Sunan Abī Daud*, ed. by Farīq Bayt al-Afkār al-Dawliyyah (Saudi Arabia: Bayt al-Afkār al-Dawliyyah, 1999), pp. 424 – 430; Muḥammad ibn Yazīd ibn Mājah, *Sunan Ibn Mājah*, ed. by Farīq Bayt al-Afkār al-Dawliyyah (Saudi Arabia: Bayt al-Afkār al-Dawliyah, 1999), pp. 327 – 383.

[810] Abu al-Ḥusayn Muslim ibn al-Ḥajjāj, *Ṣaḥīḥ Muslim*, ed. by Muḥammad Fuad ʿAbd al-Bāqī, vol. 3 (Beirut: Dār al-Kutub al-ʿIlmiyyah, 1991), p. 1573; Abu al-Ḥusayn Muslim ibn al-Ḥajjāj, vol. 4, pp. 1718 – 1745.

[811] Muḥammad ibn Ismāʿil al-Bukhārī, pp. 1131 – 1160; Muḥammad ibn ʿIsā ibn Sawrah al-Tirmizī, p. ; Abi Daud Sulayman ibn al-Ashʿath al-Sajistānī, pp. 424 – 430; Muḥammad ibn Yazīd ibn Mājah, pp. 327 – 383; Abu al-Ḥusayn Muslim ibn al-Ḥajjāj, vol. 3, p. 1573 & vol. 4, pp. 1718 – 1745.

traditional medicines and later their applications develop into modern scientific realms, products and procedures.

Notwithstanding, these sources cannot solely turn the text into proper manipulation. Following the assimilation of knowledge in science from several others civilizations including Greek and India, medicine has become a major fascinating area that had been highly developed in the early eras. There are a number of scholars who contributed to its development such as Hunayn Ibn Ishaq (d. 264 AH/877 CE), Muḥammad Ibn Zakariyā al-Rāzī (d. 313AH/ 925 CE),[812] and Al-Husayn Ibn ʿAlī Ibn Sinā (d. 429 AH/1037 CE).

Apart from being a physician, Ibn Isḥaq is also known as a translator due to his vast contribution in translating 129 of Galen's works into Arabic and Syriac[813], and book in other languages. While al-Razi, also known as Rhazes, a Persian doctor, who is famous for his valuable book *al-Ḥāwī fī al-Ṭibb* (*The Comprehensive Book on Medicine*). It contains 16 chapters that clearly elaborate the human anatomy and organs, illnesses and their treatments.

Ibn Sinā, or Avicenna, is another great figure in Islamic medicine history. He is the renowned author of an encyclopaedic work, *al-Qānūn fī al-Ṭibb* (*The Law of Medicine*). This work encompasses five books (*kitāb*) in which the first book explaines the general principles of medicine. This first part has been translated into Latin and had a boundless impact on European medical study. The rest of the books are on drugs, diseases related to specific organs, diseases related to non-specified organs and compound remedies.[814]

Ibn Qayyim al-Jawziyyah (d. 751 AH/1350 CE) also wrote in his *al-Ṭibb al-Nabawī* (Prophetic Medicine) on how both Divine revelations, i.e. the Qurʾān and Ḥadīth guide

[812] Muḥammad ibn Zakariyā al-Rāzī, *al-Ḥāwī fī al-Ṭibb*, ed. by Muḥammad Muḥammad Ismail, (Beirut: Dār al-Kutub al-ʿIlmiyyah, 2000).

[813] Max Meyerhof, 'New Light on Hunain Ibn Ishaq and His Period', *Isis,* 8 (Oct., 1926), pp. 685-724 <http://www.jstor.org/stable/223871> [accessed 19 January 2015].

[814] Al-Ḥusayn ibn ʿAli ibn Sīnā, *al-Qānūn Fī Al-Ṭibb*, ed. by Muḥammad Amīn al-Ḍannāwī, (Beirut: Dār al-Kutub al-ʿIlmiyyah, 1999).

people to understand types of illnesses and their treatments.[815] Referring to the verses of the Qurʾān, he explains that there are two types of illness, which are firstly related to the heart, and secondly related to the body. While treatment for the former is beyond natural science and is deeply involved in the spiritual belief of God, the latter is widely discussed by looking into natural remedies as had been explained in the Ḥadīth.

Interestingly, in the early era of Islamic civilization, medicine in Islam is not only observed through its technical and practical content. Given ethics is inseparable from Islamic teachings, it is hard to deny the fact that ethics had been explored and established in those days. Among the earliest literature found, expressing moral values is *Ṭībb al-Ruḥānī* (Spiritual Medicine) written by al-Rāzī, the physician. Although it is not explicitly related to physical medicine, this spiritual remedy, with an Aristotelian influence, according to him, is essential in order to obtain a better quality of life as it balances between excessive and digressive temperaments.[816]

In the 10th century, another scholarly writing was produced by Isḥāq ibn ʿAlī al-Ruhāwī (d. 4th century of Hijri) particularly on the ethics of a physician, *Adab al-Ṭabīb*. Al-Ruhāwī wrote on the values of trustworthiness and faith in the doctor and their ethical conduct; the quest of medical knowledge; the conduct of patients and the public; and the status of the doctor as a professional career.[817] The substance of this book is molded on foundational Islamic belief, despite it being disputable of the author's religious tradition. It has been proven to be the first book written on Islamic medical ethics.

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[815] Shamsuddin Muḥammad ibn Abī Bakr ibn Qayyim al-Jawziyyah, *Al-Ṭibb Al-Nabawī*, ed. by ʿAbd al-Ghinā ʿAbd al-Khāliq, ʿAdil al-Azharī, Maḥmūd Farraj al-ʿUqdah (Beirut: Dār al-Fikr, n.d.), page.

[816] Muḥammad ibn Zakariyā Al-Rāzī, *Al-Ṭibb Al-Rūḥānī*, ed. by Abd al-Laṭif Al-ʿAbd (Cairo: Maktabah al-Tuḥfah al-Bashariyyah, 1978), p. 46. This book was first published by Dār al-Kutub al-Miṣriyyah, Cairo in 731CE. It was also published by Library of Britannia and publisher of Vatican, Rome as well as adaptation by Ḥamīd al-Dīn al-Kirmānī in his book, al-Aqwāl al-Zahabiyyah (The Golden Words).

[817] Based on his writing, it was argued that al-Ruhāwī reverted to Islam due to his call for believing in Allah for Allah is the Creator of humankind, rejection of being astray from *sharīʿah* (Islamic law) and holding on faith as to be a devoted doctor. Although there is little evidence showing he was a Muslim, it is in no doubt that he was among *ahl al-zimmah* (non-Muslim who lived under the Islamic reign). See more detail in Isḥāq ibn ʿAlī Al-Ruhāwī, *Adab Al-Ṭabīb*, ed. by Murayzin Saʿīd Murayzin ʿĀsīrī, 1st edn (Riyaḍ: Markaz al-Malik al-Fayṣal li al-Buḥūth al-Dirāsāt al-Islāmiyyah, 1991)., Sahin Aksoy, 'The Religious Tradition of Ishaq Ibn Ali Al-Ruhāwī: The Author of the First Medical Ethics Book in Islamic Medicine', *Journal of the International Society for the History of Islamic Medicine,* 3 (2004), 9-11.

The literatures mentioned above has been recorded in the history of Islamic medical development. A German Arabist, Manfred Ullman, for instance, produced a historical piece on the early era of Islamic medicine. He examined in detail how the translation of the Greek, Syrian, and Indian works, all of which took place in the 9th century, and use of Persians works in the 8th century influenced the dramatic development of medicine in Arab-Islamic society.[818] Not only that, he also observed the medical background to physiology, pathology, transmissibility of illness and plague, and pharmacy that was popularised by the Arab World.

Modern medical issues have also been studied from an Islamic legal perspective (*fiqh*) by Ahmed Abdel Aziz Yacoub, in comparison with secular Western laws. His study shows that the Islamic juridical approach is compatible with modern medical law and it has the ability to progress further.[819] At this stage, it is proven that studies of Islam do contribute ways in solving issues raised in complex health and medical matters.

[818] Manfred Ullmann, *Islamic Medicine* (Edinburgh: Edinburgh University Press, 1978), p. 7 – 20.
[819] Ahmed Abdel Aziz Yacoub, *The Fiqh of Medicine* (London: TaHa Publishers, 2001), p. 286.

Appendix C

Islamic Jurisprudence on Khunthā

Religious obligations are incumbent upon all Muslim men and women. However, there are certain differences in performing those obligations 'due to limitations and alleviations arising from the respective genders'.[820] Therefore, classical Muslim scholars emphasize the Islamic jurisprudence of *khunthā* even though the prevalence of cases was relatively low among the population at large. The rulings for *khunthā* are applicable for them so long as gender is uncertain, i.e. in the state of intractable *khunthā*. In classical Islamic jurisprudence, scholars use the word *khunthā* without mentioning either discernible *khunthā* (*khunthā wāḍiḥ*) or intractable *khunthā* (*khunthā mushkil*). While explaining the Islamic legal rulings of *khunthā,* the word *khunthā* actually refers to intractable *khunthā*, rarely referring to discernible *khunthā* because for those, the signs of dominant gender is clear.[821] The rulings are discussed as follows.

Ablution

Ablution (*wuḍūʾ*) is an obligatory act prior performing prayer and *ṭawāf*, one of the essential parts (*rukn*) of pilgrimage (*ḥajj*). Ablution is recommended prior performing other acts such as reciting the Qurʾān. The act of ablution is based on verse 6, Sūrah *al-Māʾidah*. There are certain conditions that can invalidate or break ablution in Sunni schools of thought. Among these are touching another person of the opposite gender and touching private parts. The ablution is still valid if an intractable *khunthā* touches another man, woman or another intractable *khunthā*, for them could be either man or woman.[822] Like other persons, if a *khunthā*

[820] Vardit Rispler-Chaim, *Disability in Islamic Law*, ed. by David N. Weisstub and Thomasine Kimbrough Kushner (Dordrecht: Springer Netherlands, 2006), p. 70.

[821] Al-Baghāwī in Yahyā Sharaf Al-Nawāwī, *Al-Majmūʿ Sharḥ Al-Muhazzab Li Al-Shirāzī (the Compilation: An Explanation of the Rectification by Al-Shirāzī)*, ed. by Muḥammad Najīb Al-Muṭiʿī, vol. 2 (Saudi Arabia: Maktabah al-Irshād, n.d.), p. 50.

[822] ʿAlī Ibn Muḥammad Al-Māwardī, *Al-Ḥāwī Al-Kabīr fī Al-Fiqh Al-Mazhab Al-Imām Al-Shāfiʿī Wa Huwa Sharḥ Mukhtaṣar Al-Muzannī (the Great Enclosure of Understanding Shāfiʿī School of Thought)*, ed. by ʿAlī Muḥammad Muʿawwaḍ and ʿĀdil Aḥmad ʿAbd al-Mawjūd, 1st edn, vol. 1 (Beirut: Dār al-Kutub al-ʿIlmiyyah, 1999), p. 189.

touches their own private part, it nullifies the ablution.[823] With regard to *khunthā* with dual genitalia, if the person touches one of them, the ablution is still valid because of uncertainty of the 'true' genitalia. If the person touch both of them, scholars of the Mālikī and Shāfiʿī schools argue that *khunthā's* ablution is invalid.

Ritual Bathing (*Ghusl*)

Ghusl is also known as major ablution. It is the act of purifying oneself from impurity prior performing ritual obligations that the validity depends on *ghusl* such as prayer, *ṭawāf* and fasting. It must be conducted if one of these things below occurs:

1. Sexual intercourse
2. Secretion of semen
3. Menstruation
4. Postnatal bleeding for giving birth (*wilādah*)
5. Postnatal bleeding after giving birth (*nifās*)
6. Death, except martyrdom

Based on this list, the first three causes are related to *khunthā.* Scholars of Ḥanafī, Shāfiʿī and Ḥanbalī hold that intractable *khunthā* do not have to perform *ghusl* if there is penetration of a penis into their vagina, because of the uncertainty whether the genitalia is functioning or not.[824] But, it is obligatory to be conducted if there is penetration into the anus. Al-Nawāwī cited al-Baghāwī's (d. 512AH/1122 CE) opinion that if a person with dual genitalia experience both semen secretion from penis and menstruation from vagina, the person is forbidden to perform prayer, fasting and touching the Qurʾān (without translation) until *ghusl* is performed, i.e. after the semen secretion and menstruation end. The same ruling applied if the person experiences semen secretion from both genitalia. However, if the person menstruates from both genitalia, *ghusl* is not obligatory to be conducted because the bleeding might not be menstruation.[825]

[823] ʿAbd al-Raḥman Muḥammad ʿIwaḍ, *Al-Fiqh ʿAlā Al-Mazāhib Al-Arbaʿah (Islamic Jurisprudence Based on Four Schools of Thought)*, vol. 1 (Beirut: Dār al-Kutub al-ʿIlmiyyah, 2003), p. 79.
[824] ʿAbd al-Raḥman Muḥammad ʿIwaḍ, vol. 1, p. 98.
[825] Al-Baghāwī in Yahyā Sharaf Al-Nawāwī, *Al-Majmūʿ Sharḥ Al-Muhazzab Li Al-Shirāzī*, p. 51.

Call for Prayer (*Azān*) and *Iqāmah*

Azān is conducted at the start of each of the five daily prayers, while *iqāmah* is a second call for prayer conducted immediately before the prayer begins. A *khunthā* is not recommended to perform the call for prayer (*azān*) in public to avoid negative consequences. But they are recommended to do the *iqāmah* when performing individual prayer or performing congregational prayer among a group of *khuntha* themselves.[826]

Prayer

Prayer, depending on its types, can be performed either individually or congregationally. *Khunthā* is recommended to perform their prayer at home.[827] However, if they would like to perform the prayer congregationally, they should stand behind the row of men (or behind the row of boys, if any) and in front of the row of women.[828] *Khunthā* can only be an imam for prayer in certain conditions, i.e. if the followers (*maʾmūm*) are *khunthā* or if the followers are women.[829] Friday prayer is not compulsory for them, but it is recommended.[830] In terms of performing the prayer, *khunthā* are required to keep the limbs close to the body during kneeling and prostration, just like women.[831]

Attire

In most cases, the *ʿulamāʾ* take a precautionary (*iḥtiyāṭ*) approach to Islamic juridical rulings on *khunthā*. They are prohibited to wear silk just like men. They are also recommended to cover their body just like women to perform their prayer. If they do not cover their body like women, the prayer is still valid and no repetition (*iʿādah*) of prayer is required.[832]

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[826] Yahyā Sharaf Al-Nawāwī, vol. 2, p. 51.

[827] Zaliha Tak, *Khuntha dan Mukhannath Menurut Perspektif Islam (Khuntha and Transgenders in Islamic Perspective)* (Kuala Lumpur: Jabatan Kemajuan Islam Malaysia, 1998), p. 59.

[828] Yahyā Sharaf Al-Nawāwī, vol. 4, p. 291.

[829] Yahyā Sharaf Al-Nawāwī, vol. 4, p. 255; ʿAbd al-Raḥman Muḥammad ʿIwaḍ, vol. 1, p. 285.

[830] Yahyā Sharaf Al-Nawāwī, vol. 2, p. 52.

[831] Yahyā Sharaf Al-Nawāwī, vol. 2, p. 51.

[832] Yahyā Sharaf Al-Nawāwī, vol. 2, p. 51.

Pilgrimage

Sunni scholars are inclined to use rulings for women to be applied for intractable *khunthā* as a precaution step during pilgrimage. Hence, the intractable *khunthā* can perform their pilgrimage if there is a *maḥram* (a person to who marriage is not permissible) or a group of female siblings to accompany them. If there is only a group of females who are unknown (*ajnabiyyah*) to them, pilgrimage is not permitted. The purpose of having company is to ensure safety and security. When performing the pilgrimage, a *khunthā* is recommended to lower the voice while reciting *talbiah* (a repeated supplication of glorifying God) during *ṭawāf* (the ritual of circumambulation the Kaʿba for seven times) and *saʿī* (ritual walking between two places, i.e. Ṣafā and Marwah, for seven times), like women.[833] Similarly, the attire of *iḥrām* for *khunthā* is the same as for women. However, if they do not cover their head, by considering the law for men, they do not have to pay for *fidyah* (a means of compensation for a missed action or a violation of related law).

Marriage

Marriage is prohibited for intractable *khunthā* due to uncertainty of gender such that the objectives of marriage in Islam could not be achieved. If a discernible *khunthā* is married to a man or a woman, and the genitalia remain untreated, the scholars agree that it is considered as one of the possible causes to dissolve the marriage (*khiyār al-faskh*).[834]

Breastfeeding

In Islamic law, if a baby below age of two years old is breastfed by a woman with certain amount or frequency, the kinship is equated with a true blood relationship. However, these rulings are not applicable if the baby is breastfed by a man or a discernible *khunthā* who has a male dominant gender. In contrast, breastfeeding by an intractable *khunthā* is regarded as being performed by a female, and the rulings for women are applied.

[833] ʿAbd al-Raḥman Muḥammad ʿIwaḍ, vol. 1, p. 582; Yahyā Sharaf Al-Nawāwī, vol. 7, p. 245.
[834] ʿAbd al-Raḥman Muḥammad ʿIwaḍ, vol. 4, p. 164.

Inheritance

Inheritance is the main jurisprudential context that discusses the condition of *khunthā,* as discussed in Chapter 3 on the origin of the definition of *khunthā.* Inheritance has been given due emphasis in the Qurʾān, Ḥadīth and ʾijmāʿ. The very basic form on inheritance in Islam is that a man inherits twice a woman's portion of the wealth left by the deceased. The detail is explicated in *Sūrah al-Māʾidah*, verses 11 and 12. The calculations were later expanded by classical and contemporary scholars. The proportion differs according to the number, gender and kinship status of heirs who are still alive. The case is clear for discernible *khunthā,* as the rulings will follow the dominant gender. However, the scholars differ in the case of intractable *khunthā.* A general description of the scholars' views is summarized as follows:

1. Ḥanāfī scholars state that intractable *khunthā* will get the lesser proportion between two assumptions; either to be considered as a male or a female. If in any case that the *khunthā* is in the situation of being prevented from receiving the inheritance due to exclusion (*al-ḥujb*), the person is not eligible to receive any proportion.

2. Imam Mālik and Abū Yūsuf are of the opinion that an intractable *khunthā* inherits half of the proportion if the person is assumed as male and half the proportion of a female. If the *khunthā* is eligible for only one of the assumptions, then the person will receive the legally allocated proportion only. If the proportion of both assumptions are the same, then the person will receive one of the proportions only.

3. Scholars of the Shāfiʿī school state that intractable *khunthā* will receive the minimum proportion between the two assumptions of either being a male or a female, for the proportion is guaranteed and secured. The allocation of the rest of the wealth is postponed until the gender is ascertained. Otherwise, the heirs can make the decision to divide it at their discretion.

4. The scholars of Ḥanbalī school of thought support Shāfiʿī scholars' opinions on giving the minimum proportion. However, if the gender remains uncertain,

Ḥanbalī' scholars take Imam Mālik's stand, considering the half proportion of being a male and half proportion of being a female.[835]

Testimony

In Islamic law, testimony (*shahādah*) is used as attestation with regard to the rights of a second party against a third. It is used in a few contexts such as financial transactions, punishment and marriage. In criminal law, for instance, it is used alongside of evidence (*bayyinah*), oath (*yamīn*), acknowledgement (*iqrār*) and circumstantial evidence (*qarīnah*). The testimony of one man is equal to that of two women. In all cases, testimony of two men is required. If there is only one man, then another testimony from other two women is required. In this case, the status of discernible *khunthā* who is prone to a female characteristic is equal to the status of woman. In contrast, testimony of an intractable *khunthā* is not accepted.[836]

Criminal Law

Khunthā are not excluded from criminal law if they are convicted of a crime. *Khunthā's* rights and their heirs are also protected in the Islamic law if they become victims of a perpetrator. For example, the law of *qiṣāṣ* (retributive justice) provides the right to the victim or victim's heirs against a convicted perpetrator of a murder or intentional bodily injury in order to take the life of the killer if the latter is found guilty or to take retributive action towards any injury occurs. The victim is also given choice of receiving monetary compensation (*diyah*) or granting a pardon to the perpetrator.

However, in case of *khunthā mushkil* with dual genitalia, whose genitals are cut off, retributive action is not allowed due to uncertainty of the true functioning genitalia. This is because the retribution should be conducted on the same organ. Therefore, they are recommended to choose monetary compensation (*diyah*). In contrast, if the assailant is a man and the intractable *khunthā* is, later, ascertained as a male whose penis was removed, then the retributive action can be conducted.[837] *Diyah* is also known as blood money. Shāfiʿī scholars state that *diyah* for discernible *khunthā* is

[835] Mohd Zamro Muda and Amir Husin Mohd Nor, 'Kedudukan Khunsa Dalam Undang-Undang Pusaka Islam (Status of Khunthā in Islamic Inheritance Law)', *Jurnal Syariah*, 11 (2003), 117 – 128, pp. 122 – 123.

[836] Yahyā Sharaf Al-Nawāwī, vol. 2, p. 54.

[837] ʿAbd al-Raḥman Muḥammad ʿIwaḍ, vol. 18, p. 438.

determined according to the assigned gender, while intractable *khunthā* are determined according to the rulings for woman.[838]

After Death Rituals

There are four rights of deceased that should be conducted based on Islamic perspective, namely ritual bathing, shrouding (*takfīn*), prayer and burial. Ritual bathing should be conducted by a *maḥram* or by the next of kin of the deceased by taking into account ethics of performing the bath. Shrouding of the deceased of *khunthā* requires five layers of cloth just like for women. During the prayer for the deceased (*ṣalāh al-mayyit*), the imam should stand in line with the middle of the deceased like women deceased. In contrast of men, the imam should stand in line with his head.[839]

[838] Zaliha Tak, p. 68.
[839] ʿAbd al-Raḥman Muḥammad ʿIwaḍ, vol. 1, p. 470; Yahyā Sharaf Al-Nawāwī, vol. 5, p. 225.

Appendix D

Transcription of an Interview

Interviewer : Taqwa Zabidi
Interviewee : Dr. Muhammad Yazid Jalaludin
Date of interview : 17 September 2016
Medium of interview: Telephone
Type of transcription: Intelligent transcript verbatim
List of acronym : YJ: Yazid Jalaludin; IN: Interviewer

[Begin transcript 01:21]

IN: For your information, this interview is conducted to fulfil PhD research on 'Evaluation of Islamic Perspectives Regarding a Medical Condition Known as Disorders of Sex Development'. This interview is recorded and is used for the research as well as other related articles, if any. To begin with, can you share with us Dr., your experience in dealing with cases related to DSD?

YJ: Most cases of patients with DSD can be identified in the Paediatric and Endocrinology room right after the delivery. As the Paediatric Endocrinologist, I am tasked with handling patients which have been diagnosed from birth. Usually when we see any ambiguous genitalia, or genitalia which cannot be determined its gender characteristics, the surgeons will refer directly to the Paediatric Endocrinology group.

I have been registered as a 'Paed Endocrine' (Paediatric Endocrinologist) since 2006, (and received) training in September 2005 to July 2009, in which 2 years in Malaysia and 2 years in the US, at the General Hospital of Philadelphia itself. In 2009, I returned from the US and I am now a certified Paediatric Endocrinologist. I began getting involved and referred for DSD cases since my training years. Indeed, we saw many cases in a year. Mostly were cases of Congenital Adrenal Hyperplasia (CAH). In a year, we will see between 5 to 10 new patients with ambiguous genitalia. Whether they be females over virilised to male, which is the most cases, or males who are undervirilised. We can notice that there are 2 main perspectives to DSD cases, first being the CAH, and the other being Androgen Insensitivity Syndrome (AIS). CAH is more likely to occur compared to AIS. Most of the common cases for CAH are 21 hydroxylase deficiency. This means that there is a shortage of the cortisol and aldosterone hormones, which causes a lot of backflow, increasing the male hormones during the pregnancy. In most cases, this will not cause any problems to male foetuses. The problem is when the foetus is female, which would then be exposed to testosterone hormones in the womb, causing male features to form.

IN: Does that mean that during the sex determination stages the sex of the foetus changes to become a male?

YJ: Exactly. If a pregnancy is exposed to testosterone hormones, it can cause the outer features of the foetus to resemble that of a male. Here we have the Prader staging. The female usually would resemble the second, third, fourth or fifth stage. This is due to the enlarged phallus, or enlarged clitoris in females. Even though she

has no testicles, but due to the exposer to testosterone, the phallus would enlarge. She would most likely face problems in the formation of her vagina and probably there will be the problem of having one channel only. Girls usually have two channels; one for the vagina and one for the urinary tract. However, children suffering with this condition, it is as if the channels are fused into one from within. The formation of the vagina is not clear. Boys, on the other hand, only have one channel which connects to the tip of the penis. So it would not be an issue for boys as they have testosterone hormones in the pregnancy. But the extra testosterone hormones released from the adrenal glands will cause them to more virilise. This will not be noticed externally.

IN: Based on the Prader scale, does it really look like a male? How do you know that it is not a female?

YJ: That is right. If people are not familiar with these cases, these children could be classified as male. The problem comes when the child reaches the age of one to two weeks, and will start to have problems with salt content in the body. Sugar and salt abnormalities in the body can cause death. So these children may be brought back to the hospital either already dead or is in very critical condition. If they have already died, they might be misdiagnosed with bacterial infection or sepsis, as they resemble patients with sepsis. In our follow up cases on 45 children with CAH, we tend to find more girls compared to boys. Supposedly, the number of girls and boys should be the same as it is autosomal recessive. But due to the fact that doctors can identify the abnormalities in girls earlier than they can with boys, untreated boys would then start to be affected when they reach one to two weeks old, and many die are misdiagnosed with bacterial infection. That is why we do not see many boys with CAH compared to girls.

IN: The risk of death is as early as the first week?

YJ: Yes, within one or two weeks. Usually boys are more effected here because of their male genitals looking normal from the outside, and end up not being diagnosed with CAH. While with female patients, the problems can be noticed from birth so they can get early treatment. For boys who do get diagnosed early, they will be given the same medication as the girls. They suffer from salt abnormalities in their bodies, not gender disorders. When treated early, they will not have any more issues after that and tend to grow up normally as boys. Male CAH patients generally have no issues with gender confusion.

IN: So not all of the CAH cases are that of gender confusion?

YJ: Yes. If we look at CAH cases, 85% are 21 hydroxylase deficiency, the most common one. If it is a 46,XY male, there will be no confusion. If it is a 46,XX female, then there would be some form of confusion as there was exposure to testosterone in the womb. There are also some rarer cases like the CAH 17 hydroxylase deficiency and 5-alpha reductase deficiency. These cases are undervirilised 46,XY males. So they do not turn out as a normal males and their genitals do not form properly. In some cases, we could see the urethra is not reaching the top, some have the urethra end in the shaft of the penis and some end at the base of the penis such as hypospadias. There are also cases where their penis looks more like a vagina. These all are categorized as undervirilised males, but such cases are very rare compared with

cases of 21 hydroxylase. The CAH could see problems of either over-virilised males or undervirilised males. Over-virilised males will not suffer gender confusion, while undervirilised males would.

However, for cases of 46,XX CAH, there is usually a confusion due to being overvirilised. Overvirilised means that there are lots of testosterone hormone from the adrenal glands and not from the testicles, as the testes fail to function properly. During the pregnancy, the testes works to establish the internal male organs. Exposure to the adrenal hormone will then cause the overvirilisation. For patients who are undervirilised, although the foetus in the womb have testes, the adrenal glands are more functional, releasing testosterone hormones, DHT (dihydrotestosterone) and so on. If there is no presence of testosterone and DHT in the womb, even though the foetus is male, but due to the enzyme imbalance, it will not properly form, which is known as an undervirilised male. This group is rarer to find. In UMMC, as far as I know, there have only been two families who have had cases of undervirilised males. Although they suffer from testicular deficiency, but due the outside features of their genitals resembling more that of a male, they are raised up as boys. Their male organs do not work well, but they have no female organs. One case of a patient who is 20 years old, we have to replace the hormones with male hormones every month. His secondary characteristics resembles more that of males. Due to the inability of his body to produce the necessary hormones, we give hormonal injections to help his penis develops and grows.

IN: I would like to move on to the other issue of DSD, the ovotesticular DSD. Muslim scholars mention of cases with two sexual organs. However, based on my reading, it is rarely the case to find both sexual organs on one body. The cases that do occur seem to be of patients having half an ovary and half a testis. Do these cases of dual sexual organs really happen?

YJ: In my experience with ovotesticular DSD cases, formerly known as Gonadal Dysgenesis, they have both organs. I have at least three patients who suffer from this condition. And they are not Muslims, so we do not have a lot of problems in dealing with them. There was one child who had a semi-uterus, and was first diagnosed with an ambiguous genitalia. The child is seen as undervirilised male because of there could be seen one full testis and another semi-testis organ. However, when looking at the chromosomes, it is found to be a mixture of XO, XY. When further investigated, the child was found to have a full testis on one side and a semi-uterus, which is half a uterus and ovaries on the other side. The child had both a vagina and also a phallus. After discussing with the parents, we ran certain tests and determined that the male testicle was fully functional. Due to external organ resembling more that of a male despite the vaginal opening, the hole was sealed and the child was raised as a boy. So there are cases of having both genitals.

IN: Muslim scholars are of the opinion to look at the urinary tract for gender assignment? What do you think?

YJ: That is true and we cannot totally deny this view. The issue was back then we did not have advanced science and sophisticated investigation processes. So, looking at the external organ was the only possible way. Now we can penetrate into the internal organs and even into the composition of the hormones. In my view, we should combine

all these methods. We cannot just look at the external features only. For example, we would like to look at whether the hormones of a patient are functioning or not. If a patient possesses dual genitalia and the hormone is functioning like a male, but we would like to bring up the patient as a person with a uterus and strict gonad, i.e. Ovaries, that would not help. In contrast, if a patient has only one functioning testis and a male-like genital, and after a test is conducted, it is proven to be functioning well, we will be more likely to categorise the child as a male. Other parts like an orifice of a vagina, will be fixed. That is not an issue in the modern science and with today's advancement in technology. In the case of a child, we can discuss with the parents to determine whether the child is a male or a female.

IN: How early can we determine a child's gender?

YJ: For cases like this, when we know all the details, we can determine the gender within the first 6 months. Normally we can get the results of chromosomal and hormonal tests within the first 2 months. The first two months of life. I am not sure if it can be identified much earlier in other hospital. At this stage, we usually have to wait for the hormone levels to come down before we can proceed with certain simulations. The patient will have to undergo follow up sessions throughout their entire life.

As I mentioned earlier, we have a case of undervirilised Muslim siblings. The elder is 55 years old and still has follow up sessions with us. They both have follow up sessions with us for every 4 to 5 months.

IN: Classical Muslim scholars suggests to look at the external genitalia and secondary sexual characteristics and choose not to assign a gender until clear signs of male or female features appear. Having an established medical protocol in managing patients with DSD, is this recommendation is helpful?

YJ: In this situation we need to sit down with the parents. We cannot make any decisions without their consent. There are DSD groups abroad that prefer not to carry out the operation on the children at an early age. They would prefer to let the children themselves decide when they reach puberty. According to the Islamic perspective, I believe that many parents would like to identify the child's gender as early as possible in order to raise up their child either as a boy or a girl. We appreciate their interests but we have to consider the medical protocol as well. From the medical viewpoint, we do not just look at the external evaluations only. But we also have to look whether the internal organs are functioning well or not.

Functioning organs are generally not an issue in CAH patients. Although external organ is male at birth but internally there are female organs like a uterus, ovaries, as well as the 'proximal wanted' of a vagina, the only issue is with the external genitalia. But an operation can be carried out to fix the problem with the urinary tract. This is usually conducted at early age to ensure that the patients can urinate with ease and do not suffer from urinary infections. For female CAH patients, I don't see any problems in raising them as either a boy or a girl as they have the 46,XX chromosomes and [physiologically, the body] can function as females. The only issue is excessive exposure of male hormones in the womb.

Science is now trying to identify whether or not these surplus hormones affect the brain or influences male characteristics. Scientific evidence reveals that excessive exposure to testosterone since in the womb can eventually lead a female foetus to think like a male.

In the case of gonadal dysgenesis, or ovotesticular, there may be some uncertainty and parental concerns over raising the child as a boy or a girl. What we know is that both (genitalia) are present. When we are able to identify which one works and cause no harm, parents usually accept the terms on a scientific basis. This is because some diagnosis of Gonadal Dysgenesis, with the presence of the XY [chromosome], the child is at risk of developing cancer at an early stage (testicular tumour). The risk of cancer increases if the testis remains in the body; with studies detecting cancer development as early as the age 9. In these cases, when we consult parents and provide them with all available information, some choose to observe the external organs. If the external organ is functioning well, even with the presence of XY (chromosomes) and testes, the testes will be removed and the child will be raised as a boy. The only complication is fertility such as the inability to have children. But from physiological aspect, the genital is still functioning. The patient will also not have salt abnormality issues.

Another group of DSD is the Androgen Insensitivity Syndrome. There are two types (which are) complete AIS and partial AIS. All Complete AIS patients are 46,XY. They are not (within those with) 46,XX. But the androgen hormone is absent since in the womb or the androgen may be present but is insensitive. When it is insensitive, it cannot help in developing the external male organ. The child will not have internal female nor male organs but will have complete female external genitalia. They will not have any external male genitalia.

In partial AIS cases, they also suffer from sex ambiguity. These patients have 46,XY chromosome with incomplete external male organs such as the existence of both vaginal opening and phallus that cause the ambiguity.

I am currently following up 2 cases of families with Complete AIS. They are teenagers and have been raised as girls despite having 46,XY chromosome. Their external organs are of female. The male hormone is absent and the testes are not well developed and undescended.

For the partial AIS cases, there is a need to examine whether the external organs are more likely towards male or female characteristics. Previously we did not have Dihydrotestosterone hormone (DHT). The patients suffering from partial AIS will be raised as girls because even if male hormones were introduced, it would not function well. This is because it cannot change the available hormones into active hormones to develop the external genitalia. So these patients will be raised as girls. However, in the last 5 years, DHT has been introduced and it is used for patients with partial (AIS) to help in shaping the external organs and to enable it to function. It will not be as perfect as a normal organ but it will still be able to hold an erection and will be sensitive. For both cases, complete and partial AIS, the patients will suffer from fertility problems and will be unable to bear children.

IN: So, patients with partial AIS have to wait for a certain duration before gender assignment?

YJ: We would usually hold for parental consultations after all issues have been rolled out and the hormonal tests confirm the status of the patient as partial AIS. Parents would usually decide with us to raise the child as a boy or a girl. Previously, more than 5 years ago, most parents would decide for the child to be a girl. Even with the introduction of hormones, it would not be of much help as the organ would not be able to function. Recently, however, new hormones are being introduced is still unavailable in Malaysia. It is available in the UK and is already being used.

This group or groups of female CAH can sometimes get aggravated, insisting that they should be allowed to determine their own gender. This group is prone to certain problems during adolescence due to the two factors that I have mentioned earlier which are factors of testosterone exposure on the brain and thinking like men even if the foetus was identified as a female. Despite undergoing operations as a woman, they still have desire to be men. Secondly, the PAIS group (who get aggravated) when there is treatment to raise them as men. But the AIS is rare compared to CAH. When we look at the prevalence of CAH in the world and the prevalence of AIS worldwide, we will see more of CAH. Under my supervision, we only have a few people that we endorse as AIS. The remaining are CAH, which is more common.

IN: When people suggest to delay the treatment, can I argue on the grounds that medical biotechnology in those days has not progressed to the level it has today. Perhaps there were limitations in the diagnosis and treatment that makes them feel, as they grow up, that the initial decision was flawed. Such as the renowned case from John Hopkins Hospital, where John Money separated a pair of twins and assigned the male as a female. Can today's technology be of better help?

YJ: In my opinion, at this time, if we want to decide on gender assignment, we need to see it from the physical, hormonal, physiological and psychological perspectives. But child psychology is difficult to understand. Currently, in terms of hormonal balance from a chemical perspective, there are enough information for us to draw to allow us to consult parents on making the decision to assign a male or female gender to a baby. Based on my observation, there are 2 or 3 cases of Muslim children that experienced gender changed when they were 2 or 3 years old. This is because they were initially assigned as a female but developed male characteristics from the chemistry and physical perspective as they grew up. For parents, if we are able to present all these evidences before them, they are able to accept it and will raise their child in the assigned gender.

The problem is with the groups that I have mentioned earlier. The group of CAH with testosterone exposures in the womb and raised as girls because of the dominant female genitalia despite the ambiguity and the presence of internal female organs. But due to the notion that their brain was exposed to testosterone, they wanted to change their gender and became men. In adulthood, this group will face problems. From the Islamic perspective, if physical, physiological and hormonal characteristics are identified as male or female, I feel that there is no ambiguity. This is because when (approaching) teenage years, all sorts of psychological factors that lead to a desire for gender reassignment. Sometimes even men may get confused from being immersed

in emotional desire. Science shows that there are psychological effects, but are these psychological effects truly 100% accurate? Here, there are different schools of thoughts. Some say that this is due to exposure and others say exposure does not influence them as such. This matter cannot be assured to be 100% guaranteed. From the psychological perspective, everyone can say all sorts of things. What is important to me is the physical, hormonal, physiological and functional factors.

IN: Referring to the functional factor, can we consider that there will be no changes into adulthood?

YJ: For CAH women, their internal organs are still female. If they follow the treatments as prescribed, the facts so far indicate that they won't have fertility problems. Those who have problems are those who have not observed the medication as prescribed. This is what have led to their fertility issues. Even under one of our follow up cases, there is a mother who suffers from CAH and has given birth to children without any assistance. This shows that they can conceive normally as long as they follow the prescriptions accurately. For the undervirilised CAH male, we prescribe hormones but it cannot improve fertility because the testes cannot function well. But science today has begun to introduce technology that can improve fertility rates. Before this there were cases of kallmann syndrome. This doesn't involve ambiguous genitalia but patients cannot be assigned to a male gender because the brain cannot signal its development as a male. Previously, when we see such cases, we will say, "I'm sorry, zero fertility". But today, treatments exist. Some can successfully have children. We can never say never because science evolves. If we want to discuss one thing, we need to refer to many other things. To me, even the undervirilised cases may be treated for fertility one day. We never know. So, functionally, it cannot function on its own (but) it can be assisted through hormonal therapy.

For the CAH virilised male, these cases do not have issues with fertility and functionality (genitalia). As long as they take the medication as instructed. Their problems are in terms of salt content as they may have a shorter life expectancy due to salt content abnormalities and not due to other problems.

IN: What are the challenges in managing Muslim patients with DSD?

YJ: I think most Muslim parents want certainty. Even for patients with 46,XY, when we confirmed that the genital cannot function as a male, most parents were content and had no objections once they got professional opinions. For older teens, their parents seemed more relieve because their instincts told them their child looked like a boy, but the doctor identified the child as a girl at birth.

There were many parents that relieved. For instance, the case of the undervirilised male that I raised as a man, although his genitalia were not perfect, his parents had wanted the child brought up as a boy because they were still hopeful that their child would grow up to be a man. So they are ok with that decision.

For cases of with Complete Androgen Insensitivity, despite being 46,XY, their external organs were completely as of female and tests confirmed that there are risks for the child to be raised as a girl. The parents agreed to raise their child as a girl. From a

medical point of view, I think as long as we can provide evidence for the parents from functional and hormonal perspectives, the parents usually accept the recommendation.

IN: Muslim scholars are of the opinion that, if there are no dominant signs of being either male or female, the patient can remain as is and live as khunthā or hermaphrodite. Do you think this is acceptable in medical perspective?

YJ: When I say *khunthā wāḍiḥ* and *mushkil,* that is being certain or uncertain, this what we classify as DSD. For type 46,XY or 46,XX DSD, would 46XY DSD be grouped under AIS, does would it fall under mixed gonadal dysgenesis, ovotesticular DSD or just ... to me there is still too much we do not know about the science of DSD. But if these cases were assessed by a doctor through examining their genitals and hormone functions, I think they can still be classified under any of the DSD. The only problem is for those who do not come forward for medical treatment. Then they think they are hermaphrodites and continue to be so. There wouldn't have been any issues if they were to see a doctor. For example, I recently received a case of a 17-year old teenage girl who was raised as a female. The teen was successful in sports and was referred to us because the teen wasn't menstruating. Upon an examination, we found that this teenager was actually a boy. The gender is male, with male genitalia present even though there was a vagina, but with testicles on top of it and not in the scrotum. After carrying out a hormone test and physical examination, we found no female internal organs present despite the presence of a vagina on the outside. This is one of the cases where we question whether it is PAIS or undervirilised male CAH, such as 5-alpha reductase and so on. This is where we would ask the opinion of a few others, where we seek explanation on whether a genetic molecular is present and that the patient doesn't have a 5-alpha reductase deficiency. In my opinion, this kind of cases if not assessed by a medical expert, it would not be treated and the patient will make self-decision. An expert would be able to find the source of the problem and the condition can be treated correctly. I have brought this (case of the) female teenager to JAKIM and made a gender reassignment. We have carried out an operation to lower the testicles. Only minor operations would be made to correct the urinary tract to pass through the vagina. So, all this while, this teenager was raised as a Muslim and was told to dress like a girl even though he knew that he was (rightfully) a boy. When asked on how he is doing these days, he is happy because he knows that he is a boy despite having a vagina, having to urinate sitting down like a girl, but being certain that he is a boy. In this case, in my opinion, the outside features look 'mushkil' (uncertain), but when experts can assess the physical and hormonal elements with the technological advancement we have today, we can request to have the molecular genetics to be assessed. We have much more evidence to say whether this is truly a khunthā wāḍiḥ or mushkil. The mushkil cases are the ones that always have been decided by themselves without the correct medical procedures. In my opinion, the cases that do not seek medical treatment are the ones that end up being problematic.

IN: Through medication, is there a possibility that cases of khunthā (hermaphrodites) mushkil will no longer persist due to the medical technology being able to help to identify a dominant gender?

YJ: That is right. If brought to medical attention, 'insha-Allah' it can be solved. With the development of science over the last 20 to 30 years, many problems can be solved if

they are brought forward. It is just that so many of the patients make their own decision to be female. Chances are that some may be right, but because they have not undergone the right procedures, problems may emerge later.

IN: Ok Dr, in terms of making decision, with the multidisciplinary team at PPUKM, does the representative of Islamic scholars, matter?

YJ: To me, with a representative (of Islamic scholar) in the team, at preliminary level of discussions, we already have someone who can give opinion from the Islamic perspective. I prefer that approach instead of having to bring the case to JAKIM without anyone else providing an Islamic opinion before being taken to JAKIM. When I raised the case I mentioned just now, to JAKIM, to be presented in Seremban, at least I already have someone from JAKIM to meet with the patient and his/her family. We already have preliminary health screens from the Islamic perspective. When I concluded the case, Ustaz Tarmizi met with the patient and her parents, before I took it to the Panel of Syariah Experts JAKIM, consisting of almost 20 people. When we took and presented the case there (Shariah Expert Panel's meeting), we also need to consider the Islamic perspectives. So, I think involving JAKIM at the early stage of the process within our team, is crucial. Because we lack the Islamic knowledge. I would know the chemical perspective, like hormonal responses. But from the Islamic perspective (the question is) whether we can or cannot (carry out a gender reassignment)? We want our decision to be in line with the Islamic rulings without any contradictions. If there are contradictions, we want to be able to come to a middle ground to treat the patient. We do not want to get over-excited about prescribing anything (treatments). For example, the patient may want to change the gender, but it may be against Islam. Sometimes, we fear of being manipulated by the patient, like the group of CAH women who at the end of the day wanted to be men. We do not want to be manipulated as doctors. For instance, they may be female from the physical and hormonal aspects, but they are psychologically male due to testosterone exposure. We do not want to do something contradict with religion.

IN: Do you think religion is perceived as a boundary?

YJ: Yes, when there is an officer in the group, I believe it helps.

IN: Or perhaps you feel that there is no need to involve the Shariah Expert Panel as long as there is representation within the group?

YJ: To me, if the representatives are already experts, who are trained to discuss Islamic issues and DSD, and they come from a scientific background, I would have no issues with it. But if there are no experts and we would still require the opinion of the Sharia Expert Panel, I am not against meeting and addressing this to members of the Panel because a collective decision is always better than an individual decision.

IN: Perhaps the decision of the could help when dealing with the National Registration Department?

YJ: Yes. Calling the Expert Panel means that it will come with relevant expertise. Each panellist will have their own expertise and with it, a particular view. These views are what I think are important so that they are in line with my own judgment.

IN: What about the timing for the meeting, since the Shariah Expert Panel would have their own schedule and requires an attendance quorum? Do these matters would delay treatment?

YJ: For cases that require quick decisions, these meeting do delay them. This happened to that teenage athlete that required early surgery, but we could not push it because the meeting was postponed. To me, these things can be resolved. There are some cases that require immediate action but it depends on willingness. This is because the Shariah Expert Panel convenes to oversee a wide range of issues, not just DSD cases. I think that would be better if there could be its own panel for DSD cases consisting of several people and to be called when there are urgent cases which need decisions to be made. This is because postponement may cause other issues. Sometimes the patient may face difficulties, like in my patient's case. He had no choice but to postpone his SPM examination because he needed to confirm his gender reassignment first. The process of gender reassignment required the approval of the Shariah Expert Panel, followed by the National Registration Department and the National Registration Department took several months to make a decision. This is what I think that should be improved.

When asked whether the Shariah Expert Panel is important or not, I say it is. This is because they have a range of views. When I made a presentation, I received questions from the various point of views such as scientific and legal background. They themselves wanted to understand the problem from multiple angles.

IN: Are their questions helpful?

YJ: The questions raised were expected such as how it functions, how long will the surgery and recovery take and so on? To the Shariah Expert Panel, what is important is that after the operation, the organ would function either as a male or female. And that actually depended on our recommendations. But personally, I think they asked these questions because they wanted to fully understand the issue. They wanted to know what we done so that we can deliver the treatment at the patient's best interest. So, we as the doctors aren't just making decisions arbitrarily. It is more about mutual concern for the patient.

IN: What about the issue of confidentiality the case?

YJ: To me, raising the case to the Shariah Expert Panel requires the patient's consent. We ask the patient's consent for medical procedures such as operations and tests, so that the same on taking the case to the Panel. We must be transparent from the beginning. I do not think that there will be confidentiality issues as long as the patient consents.

IN: Does the fatwa help in managing patients or does it contribute to confusions since each case differs from one to another?

YJ: I think the fatwa is important as a guide. It is just that we cannot completely accept it 100% for every case as it differs from case to case. The fatwa in itself, to me, is a guide because we cannot diverge from what is allowed (in Islam). To me, the fatwa is

crucial as a general guide, but each case needs to be assessed individually. Each case, whether it is a CAH or AIS, as I have explained earlier, is different. The ambiguity level is different. Generally, they may have histological issue with regard to hormone and psychological problem in adulthood. Psychological problem is unseen in children. However, by the time they reach adulthood, the psychological problem comes in. If we consider fatwa as it is, the psychological issue would be a problem because how do we take it into account?

IN: So, does this mean that fatwa should just be a general guideline? Such as a fatwa in Saudi Arabia only mentions the word *'alāmāt'* or signs for gender assignment without clearly mention whether it refers to chromosomes, hormones or other factors?

YJ: Yes, the fatwa must be a general guide. We do not need to mention the diagnosis because there are various cases. So, generally the fatwa like in Saudi Arabia that mentions the symptoms of ambiguity, are more general and is the best practice because it is used as a guidance and not as a binding blanket solution for all cases. When we clearly mention CAH or AIS, it is binding. The fatwa must be a guidance and not the deciding factor.

It does not have to be too general. But more towards scientific nomenclature. Previously, cases such as these are classified as hermaphrodite. But between 2006 and 2008, a new term emerged which is DSD. In terms of the fatwa, it can evolve in accordance to scientific facts. When there are changes like that, it would develop in parallel instead of using outdated approaches.

The fatwa needs to be general and does not need to be detailed, which would be enough to be based on the karyotype or pathological factor including chemical and hormonal elements. Some Arab states that release fatwas according to physiological and hormonal factors, their fatwas are still medically relevant.

IN: As a way forward, do you think there is a need to incorporate Islamic perspectives and medical frameworks to manage patients with DSD?

YJ: Both sides must work together like what we do in PPUKM. This is a good approach as we require parallel views between the science and the wider Islamic perspective. When we have been in discussions from the beginning with officers of Islamic affairs, it will be good for the patient. When I raise my patient's case, that I mentioned just now, to the UMMC Ethics Committee, I was asked, "Why is this only done for Muslims?" The one asking the question is a Chinese. "Why can't this be extended to other religions?" I responded that, "this research project is to help pave the way because we found the cases are more complicated than usual as they involve many organizations. For those non-Muslims, if they want to change their gender, they can do it on their own. But Muslims cannot do that. We do this because we can see problems arising." I think when we start with doing the difficult ones first, the other less complicated cases would also then be much easier to work on.

When we create the pathway to make it easy for Muslims, others can also see it as a guide because I think other people also have their own perspectives. It is just that nobody comes forward because normally, they take their own actions, they make their own decisions, then they just stick to that decision without religious input. To us, for

patients that come and want to know, and they do not want to make the wrong decision that would cause the wrath of Allah. That is the reason why we come forward. Other religious adherents may not have the same thinking. We would not know if they feel something in their heart. Maybe they think about it but do not know where to go or where they can turn to. At least, when we have things like this, once it has been done and they have their own scholars, maybe they would need our input.

[End transcript 1:27:34]