

A Religio-ethical Approach in the Management of Newborns with Disorders of Sex Development (DSD) in Malaysia*

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Summary. Ethical issues related to Sex Assignment Surgery (SAS) in newborns with Disorders of Sex Development (DSD) range from concerns of the rights of newborns, the reliability of the consent of parents and the paternalistic disposition of physicians. Wrong assignment of gender is held as an ethico-legal risk and the rights of the 'true gender' are denied because roles and responsibilities for the Muslim differ according to gender. In this article, the issue is discussed in the context of the Malaysian culture where distinct religious requirements dictate how decisions regarding SAS ought to be made. Information on the application of religious principles in decision-making in Islam is gathered through interviews and public documents. It is found that assigning the appropriate sex for DSD newborns is regulated in Islam which recognizes the role of the DSD individuals, or *khunsa*, in the society. In this paper, we argue that moral decisions regarding SAS ought to also include socio-cultural considerations. The role of ethics that unifies medicine, religion, and the humanities is examined. A new ethic is proposed whereby the panel of decision-makers includes not only the parents of the newborns, the attending specialist, and the usual assemble of experts but also religious scholars, priests or gurus. While the medical experts may provide advice on biomedical matters, the inclusion of a Muslim scholar is imperative when the newborn of a Muslim family is enlisted for SAS. Proper assignment of gender is demanded by the Islamic laws of which wrong gender choice has crucial implications for the intersexed in adulthood. A multi-disciplinary team (MDT) such as the one proposed in this paper will ensure that the sustainability of values within a religious and culturally-based society is preserved.

Keywords: Sex Assignment Surgery, Intersex, DSD, ethico-legal, multi-disciplinary

Introduction

Bioethical framework of assessing moral issues in medicine, bioethical evaluation should include other perspectives such as religion, humanities and social sciences (Silber 1982). Veatch (1972) proposed that "*moral problems involved in medical care are too important to be left to doctors alone.*" In fact, Bioethics which arose since 1960's was a part of efforts to change social practices in medicine and research (Cahill 2003, p.363).

Therefore, through this paper, a different approach in bioethics which unifies religion, humanities and social sciences reflects as a comprehensive foundation to build a framework of multidisciplinary team (MDT) as a practical medium to accomplish ethical decision making in medical realm. The issue of sex assignment surgery (SAS) for newborns with Disorders of Sex

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Development (DSD) is approached as a case study by reviewing its complex interactions of biological, psychological, social, and cultural factors.

Disorders of sex development (DSD) which are commonly characterized by ambiguous genitalia is not uncommon in Muslim communities and ambivalence regarding sex assignment and reconstructive surgery in those DSD newborns has plagued these communities for a long time. Cross-cultural studies show that families in Muslim-predominant countries such as Turkey (Gollu et al., 2007), Saudi Arabia (Taha, 1994), Malaysia (Kuhnle & Wolfgang, 2002), and Morocco (Repetto, 1972) tend to select the male gender for children who present with ambiguous genitalia for several factors such as the likelihood to achieve economic independence, culture and religion, family and educational background.

The issue of SAS on DSD newborns has presented cultural and socio-psychological dilemma due to improper gender assignment in early childhood surgery (Kessler, 1998; Warne & Raza, 2008). The concern has perplexed parents and doctors and this situation is aggravated by societal demands which seem to reject a 'third gender' but place dire importance on the male-female identity (Mohamed and Noor, 2014).

SAS has been acknowledged as an acceptable standard of medical practice since 1970s to treat serious genital injuries (Diamond and Sigmundson, 1997). However, the practice SAS brings about several ethical concerns (Beh and Diamond, 2000) such as the rights of newborns consent of parents (Kipnis and Diamond, 1998), inappropriateness of early surgery (Creighton and Liao, 2004) and the involvement of physicians often dubbed as paternalistic (Chase, 1998). Therefore, it is pertinent that the management of DSD is developed in a manner that places central focus on the interest of the newborns and which is corroborated with a clear reflection of the socio-cultural implications of improper or 'inaccurate' gender assignment (Mohamed and Noor 2014).

Silber has noted that not only is the engagement of ethicists and theologians pertinent, these scholars also deserve to be given a thorough explanation of the whole process within a SAS protocol from diagnosis to prognosis, so as to be able to provide a morally decent and sound judgment on the issue (Silber, 1982).

This paper will begin with ethical problems of SAS to DSD newborns, and eventually each of those problems will be critically examined so as to see the rationales of having MDT as a holistic approach to find an ethical solution to the problems. A suggestion on an Islamic bioethics that may be considered as 'pragmatic' to solve the problem of SAS on DSD is supplemented by a couple of interviews involving paediatricians and religious scholar. This paper, hence, eventually suggests the employment of a multi-disciplinary team (MDT) of scholars ranging from the medical, in the field of neonatology, endocrinology, urology, gynaecology and, genetics, the psycho-sociological and most importantly, the religio-ethical consultants.

Sex assignment surgery (SAS) and disorders of sex development (DSD)

Surgical intervention to treat intersex newborns with genital anomalies began in the late 1950s and become a standard procedure in 1970 for the correction of such problems including ambiguous genitalia and serious genitalia injury (Beh & Diamond, 2000). Intersexed individuals are those who are born together with male and female biological features simultaneously. For instance, they might have one ovary and one testes, or gonads that contain features of both ovarian and testicular tissue. They can have chromosomes of XXY and XO, and other configurations. There are more than a dozen categories of intersex (Hughes et.al, 2006). The

most common types of intersexuality are Congenital Adrenal Hyperplasia (CAH) and Testicular Feminization Syndrome (TFS) (Hewitt & Warne, 2009). In both cases, it can be clearly seen how genetic sex and phenotypic sex do not match, and could eventually cause an ambiguous genitalia.

CAH is an inherited disorder that occurs when the adrenal glands of an "XX" (female) individual do not function appropriately. In this case, there will be both cortisol and aldosterone together with excessive amounts of androgen hormones. The imbalance of hormones before birth may cause some girls to have ambiguous genitalia (WSDOH, online). On the other hand, Testicular Feminization Syndrome (TFS) is a genetic disorder that makes an "XY" (male) individual become unresponsive to androgens i.e. male hormones that produce masculine characteristics. Therefore, the individual appears like any normal girl, despite they possessing "XY" chromosomes (Dredger, 1998).

Social and ethical challenges towards the contemporary protocol of SAS

Since 1960s, newborns with DSD have been managed via medical intervention based on the theory of "human are psychosexually neutral at birth" (Diamond and Sigmundson 1997). This intervention became standard protocol in the management of DSD until mid-twentieth century in the United States and other countries from the early 1990's however, various critics about standard DSD' management have emerged from social activists and scholars from various multidisciplinary fields such as medical (Diamond and Sigmundson 1997; Kass et al. 1996), social science (Dreger 1998; Slipjer et al. 1998), humanities (Fausto-Sterling 2000; Kessler 1998), feminism (Dreger and Herndon 2009; Butler et al. 2000), and law (Hermer 2000; Bird 2005). These scholars argued that management of DSD only involve a singular approach of medicine and thus, it fails to resolve the conundrums behind the controversial issues of SAS to newborns with DSD.

By viewing the issue of SAS and DSD from multiple perspectives, perhaps, a better ethic may be formulated to grasp the heart of the problem.

i. The problem of "nurture-based theory"

A medical intervention policy for newborns with DSD which is perceived as 'optimal gender policy' is based on research by John Money and his colleagues of psychosocial Research Unit of the John Hopkins Medical Centre (Creighton and Liao 2004). According to this policy, the intervention aims most likely to maintain reproductivity, good sexual function, normal-looking genitalia and a stable gender identity (Hester, 2004; Ismail, Phak and Thomas 2012). This policy is founded on the "nurture-based theory" which claims that gender identity has nothing to do with nature, but everything to do with nurture (Diamond and Sigmundson 1997). This policy or guideline remains applicable to determine "optimal gender" made by physicians when presenting options to parents. For instance, some national organizations in Europe have published similar guidelines, and recent articles from the Middle East and India suggest a worldwide acceptance of the practice (Hester 2004). In Malaysia, similar policy or guideline is adopted but with reservations: the final decision lies on the socio-cultural concerns of the patients and their families (Ismail, Phak and Thomas 2012).

In the case of DSD, many physicians are still more prone to emphasize that a healthy psychosexual development is dependent on the appearance of their genitals (Diamond and Sigmundson 1997). Therefore, in most situations, decision on the choice of gender assignment is based on the predominant appearance of the external genitalia and they are most commonly assigned as females (Schober 1999; Wilson and Reiner 1999). The reason for selecting female gender more than male is because it was believed that prenatal exposure to androgen did not affect the developing brain in humans and that making genital appearance of the female by surgical intervention, in combination with the child's nurturing by the parents, would result in the development of a stable gender identity (Diamond and Sigmundson 1997). Another reason of doing that is because it is harder to fashion the male genitalia in comparison with the female's (Lev 2006).

This protocol however is now being challenged because of the asymmetric way in treating femininity and masculinity. In addition the greater likelihood of fashioning female genitalia compared to males implied that physicians seemed more keen to preserve the reproductive potential of babies born with ovaries rather than babies born with testes (Dreger 1998).

In Malaysia, gender assignment is determined based on the following guideline which is based on the International standards (Ismail et al. 2012):

- 1) "genetic females should always be raised as females, preserving reproductive potential, regardless of how severely the patients are virilised
- 2) "in genetic male, however, the gender assignment is based on the infant's anatomy, predominantly the size of the phallus"
- 3) Assigned female: remove all testicular tissue, vaginoplasty after puberty, and no place for vaginal dilatation in childhood
- 4) Assigned male: orchidopexy (move an undescended testicle into scrotum), remove all mullerian structure, surgical repair of hypospadias and gonadectomy to be considered if dysgenetic gonads.

In most situations, sex chromosome is the main determinant for sex assignment. Even though in the case of DSD for instance the case of complete AIS, where the sex chromosome is totally unmatched with phenotypic appearance of the newborns, DSD is primarily being categorized based on sex chromosomal configuration. (Hughes et al. 2006)

ii. Early or later surgery?

In most DSD cases, there is a continuing debate about the timing of the surgery; whether at the early childhood surgery increases quality of life, as well as sex and gender role satisfaction (Creighton, Minto and Steele 2001). Based on the earliest policy, management of DSD is usually regarded as medical urgency (Wilson and Reiner 1998). Although some DSD are not life-threatening, except those "salt-losing category of CAH and gonads prone to malignant tumors, parents are advised by physicians to quickly establish the babies' optimum sex (Kessler 1998).

In the last few years, discussion regarding SAS as the recommended medical treatment for DSD individuals has brought more criticisms, in particular, people who have had SAS during their infancy have been critical about the procedure ever since (Fausto-Sterling 2000). This critical discussion was initiated by adult patients who opine that the medical treatment of their condition was inadequate and/or wrong (Chase 1999). There are claims that surgical techniques have enhanced functionality, yet, up to now, no decisive evidence (Creighton and Liao 2004). The appropriateness of early surgical intervention is never well supported by proper scientific studies by which some of them disprove its effectiveness (Reiner 1996).

iii. The Rights of newborns (child) and limit of parental authority

Any medical treatment, as a regulation, has to be justified by an informed consent of the person affected or by his or her legal representative when the person is not capable of making his or her own decision. The right to self-determination is acknowledged as a fundamental right in health care. The clinical management of newborns with DSD (paediatrics practice) makes no exception to the rule. Also, article 12 of the United Nations Convention of the Rights of the Child (CRC Convention) asserts that “States Parties shall assure to the child who is capable of forming his or her own views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child (Convention; United Nations, 1989). At any time of SAS, the decision making must be based on prognosis from biological and social perspectives. The decision making must also consider the need of the young child and the importance of parent-child relationship. Parents, as the child’s most important attachment figures and legal representative, have to be included in the decision-making process (Greenberg 2006). Health care professionals should highly consider the optimal physical, emotional and social development of the child, trying to maximize the child’s and future adult’s participation in decision making on the one hand and a good parent-child relationship on the other (Wiesemann et al. 2010). This statement shows that, in the condition whereby the babies unable to make decision, parents can be the best representative to make the decision of behalf of their baby, after all the proper inspection has been done by physicians. According to the convention, persons, including the children are rational moral beings are autonomous and self-determining individuals who determine their own moral values and perceptions of the good life. In paediatric medical decision making, focus is usually placed on protecting the child’s “best interest” in terms of the child’s equality and liberty interest. In this context, as stated by Cherry (2010), “parental authority is re-conceptualized in decision making to give priority to the child’s own self determination, self-realization, individual equality, and actual or potential autonomy” (Cherry 2010). However, the role of the parents is still important in providing direction and guidance in the exercise by the child of his or her human rights (Ringhem 2007). In addition to that, the convention presumes the role of government and political authority to endorse public policy to protect the rights of children with no regard to parents’ permission or interests (Ringhem 2007, p.245). Therefore, it should be noted that, in decision making, parents should consult the expert members of MDT in order to arrive at best decision. In this case, parents may not be the absolute decision maker and they should respect any decision that is intended to protect their child’s “best interest”.

iv. The issue of medical paternalism

According to Larcher (2005), although physicians have a duty to act in the best interests of their patients, objective standards of best interests for children may be hard to be defined in isolation. This is because the “best interest” must be understood within a bigger picture. In DSD management, there may be tensions between the potentially conflicting obligations of respecting a child or young person’s right to make an informed voluntary self-determined choice (autonomy) and providing treatment for the child that carries more benefit than harm. Moreover, any consideration of child’s best interests needs to include the obligation to respect family and parent-child relationships (Inwald 2008).

The long term outcome of SAS is known to be uncertain due to lack of information and in some situation, information about the diagnosis, the efficacy of the treatment, and complication may be incomplete, and clinicians fail to impart accurate and complete information. One example of advice to parents in describing DSD is that, the child was “sexually unfinished” (Nussbaum 2000). Parents are always being told that physicians are not “changing” something fundamental about the child but are merely “finishing” the child’s incomplete anatomy (Fausto-Sterling 2000). In the consultation session, the advice would usually be concentrated on creating typical appearing genitals and correcting the genital ambiguity by SAS and careful rearing. However, sex determination and sex differentiation are far more complex than the child’s genital appearance (Diamond 1976). This is due to the fact that the alteration of genitals does not affect the biological determinants of sex. Therefore the issue cannot simply resolved by SAS.

In a way to produce ethical decision, parents should be informed about detailed information about the condition, such as the efficacy of treatment and available alternatives of medical techniques, as well as possible future outcomes including lifelong medical and hormonal treatment. Parents may respond differently depending upon their level of education and socio-economic background for instance, therefore they may perceive the nature of treatment differently (Catlin et al. 2008) and lead to wrong decision. Certainly it was the obligation of physicians to provide them with adequate information.

The importance of multidisciplinary team (MDT): preliminary view from Malaysia

Successful management of SAS and DSD does not only depend on medical objective but also other aspects such as social, culture and religion. In medical aspect, consideration such as minimizing physical risk to child, minimizing psycho-social risk to child, preserving potential for fertility and preserving the capacity to have sexual relations are vital parameters. In this regard, SAS or management of newborns does not merely aim to fashion a normal-looking and functioning genitalia, but also psycho-social wellbeing, stability in gender identity and recognition of their role in society. All these consideration is important to ensure that the decision is in the best interest of the child (Hughes et al. 2006; Houk et al. 2006). Therefore, SAS must be avoided before experts’ evaluation in management of newborns is established (Ismail et al. 2012).

Some researchers especially those from the medical field such as Brain et al. (2010), Al-Jurayyan (2011), Zainuddin et al. (2012), El-Sherbiny (2013), Ozbey and Etker (2013) have critically stressed on the importance of multidisciplinary approach in resolving the medical dilemma. They were concerned about the huge challenges faced by physicians who need special assistance and knowledge from other non-medical sources to deal with certain medical dilemma. In the issue of SAS and DSD, sex assignment and management plan, in some cases, need to be decided in such a brief time. Thus, maximum precaution must be strictly observed to avoid wrong decision and misconduct protocol. This situation as portrayed by Hughes et al. (2006), calls for a comprehensive multidisciplinary team.

In some cases of DSD where diagnostic test and physical examinations are not decisive in decisions regarding sex assignment, it is important to engage psychologist, ethicist and religious scholars whose roles are to provide time and space for discussion. The importance of those scholars is not about pathologising DSD but rather is recognition of exceptional personal and social challenges that a diagnosis of DSD presents. The process of sex assignment is not only about making a decision but also an opportunity to process what has happened and set out plans for the future.

In this research, we highlight the important roles of the non-medical team such as ethicists, religious scholars, clinical counsellor as well as other related disciplines which may contributed towards a holistic understanding of the issue. Be as it may, we focus on the significant role of physicians to be transparent in providing sufficient knowledge and information to other members of the team for them to fully understand the condition of DSD and the nature of SAS. The flow and exchange of information between those experts are very important to critically analyze the issue in diverse perspective so as to produce an effective and ethical decision. Therefore, all professionals involved with the management of the DSD newborn should be well-informed, that is, if there is any doubt the sex of the baby should never be guessed. A paediatrician should counsel the parents in the first instance, and outline a clear plan for further management. In some cases, DSD are not a medical emergency in itself, so, parents-newborns interaction is essential and the child should not be unduly 'medicalised'. However, the adrenal insufficiency associated with some forms of DSD can become an emergency if overlooked and not treated early. Therefore, early management of DSD requires detailed medical examination by physicians and medical team and they are responsible to provide data for further evaluation by other members of MDT to make the final decision.

Other than important involvement of scholars and expertise in MDT, the involvement of parents is vital. In fact, open communication with patients and family is essential and encouraged. Importantly, patients and family concerns particularly regarding social and culture should be respected and gender assignment must be avoided before an expert evaluation in newborns with DSD is received (Ismail et al. 2012).

In figuring the model of comprehensive MDT, the following diagram 1 illustrates an overview of the multidisciplinary team (Brain et. al 2010). This framework model can be use as a foundation to create MDT in Malaysia by stressing the importance of those non-medical experts in religion, humanities and social sciences.

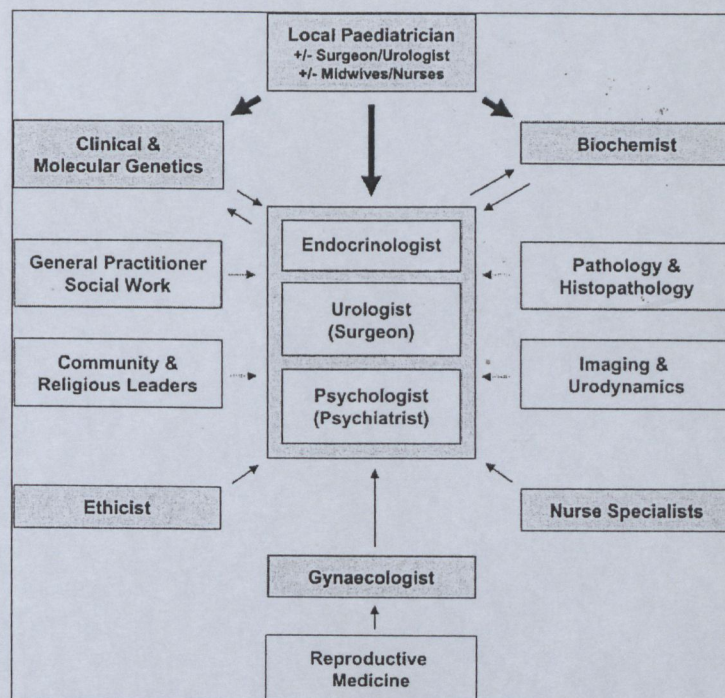


Diagram 1: the model of multidisciplinary team (MDT) in hospitals (Brain et.al, 2010)

The decision for surgery and the timing should be made by the parents, together with the endocrinologist and paediatric surgical team, after a complete disclosure of all relevant clinical information and all available options have been discussed and after informed consent have been obtained (Ismail et al. 2012). Decisions concerning sex assignment and associated genital surgery must consider the culture in which child and his/her family are embedded (Ismail et al. 2012). At this stage, the role of those non-medical experts comes into the place. Such comprehensive information provided by physicians and other expertise may effectively assist experts in religion, psychology and ethics to weigh the decision. To this end, the issue is not only a medical concern, yet, it becomes a personal matter which affects life and future of the affected individual.

Since SAS is adopted from the western medical protocol, it is also embedded the western biomedical discourse which apparently different with local discourse which so much influence by the religion and culture. Therefore, in the context of Malaysia where the role of culture and religion is significant, the notion of SAS and DSD must be seen independently from the western point of view.

In Islamic perspective, accurate decision-making with regard to SAS is very important since it affects the future of the adult intersexed in matters concerning 1) religious occupations, 2) their rights to inheritance and, 3) particular designation of roles and responsibility in communal life (whether as potential leaders or followers). The choice of gender for the DSD child stands as an important problem in contemporary Islam because sex and gender role behaviour is framed within Islamic law. The division of property in Islam is assigned according

to gender. Women “shall be legally entitled to their share” (*Qur’an* 4:7) and that “to men is allotted what they earn, and to women what they earn” (*Qur’an* 4:32). “Only if women choose to transfer their property can men regard it as lawfully theirs” (*Qur’an* 4:4).

Islam plays an important role in the daily affairs of the Muslim individual, which includes moral matters affecting the family and inheritance and, civil aspects of the life of the community. Such matters are deliberated within a frameworks of values and usually derived from the broad ethical teachings of the primary sources, the *Qur’an* and the teachings of the Prophet Muhammad, the *Sunnah* and secondary sources namely, the *ijma* (consensus of religious scholars), *qiyas* (analogical reasoning) and *ijtihad* (intellectual reasoning) (Kamali 2003). Interpretations of Islamic law provide Islam the dynamism that enables it to respond to modern medicine and all associated innovations (Daar 2001). New moral problems are subsequently addressed through the formulation of *fatwas*, religious edicts that provide broad guidance for the individual and the society. Islamic law or the Shariah seeks to achieve the realization of the *maslahah* or public interest. Accordingly, the realization of public interests lies in the safeguarding or the protection five human interest or benefits, namely, life, intellect, progeny, inheritance and faith (AbdelKader 2003). Moral dilemmas involving medical treatment are often deliberated alongside these five human interests. For example, the problem of post mortem was initially prohibited in Islam, on the basis of the action violating the body of the dead person. There is value in preserving the dead body as a whole (Budiani 2007). However, in appraisal of the potentiality of many more lives that stands to be saved, the act of removing organs and transplanting into needy patients was later declared as a necessity. Would the same lines of deliberation be applied on the ethics of the issue of the DSD child? Support for medical intervention in many Muslim countries is generally given on the basis of preventing human suffering and ensuring family wellbeing. On the basis of alleviating suffering and prevention of death of the case of the congenital adrenal hyperplasia (CAH) child, sex assignment surgery may be perceived as a necessity. Sex assignment surgery has been performed in many CAH cases in Muslim predominant countries (Al-Maghribi 2007). The CAH condition if left untreated can lead to salt loss and subsequently, shock and impending death (Al-Jurayyan 2011). The mean age at onset of the salt-losing crises in affected infants is noted as 9 days in females and 25 days in males (Al-Maghribi 2007) and hence the urgency of early surgery is justified on this finding.

In 2003, a preliminary effort to initiate multidisciplinary discussion on the medical dilemma within religious perspective has been carried out through one seminar which was organized by The State of Perak’s Religious Council. The seminar was aimed to establish a body which unites scholars from religious and medical field to discuss various medical dilemma and religious matters (Personal communication, January 7, 2011).¹ In 2004, a prelude discussion on the issue of DSD within the multidisciplinary framework has been initiated by Malaysian Islamic Development Department (JAKIM) in 2004 which involved some paediatrician from the Malaysian hospitals. However, the efforts have not come into realization since the progressive follow up from those parties was nonexistent.

In the local hospitals, the formation of MDT is ideally reflected by a mutual discussion among physicians from different medical expertise such as paediatric, surgery, urology, gynaecology etc. The increasing concerns about idealistic framework of MDT have been

¹ Personal communication with Head of Pediatric Department, Putrajaya Hospital, Malaysia dated January 7, 2011.

reflected within the 'Paediatric Protocols for Malaysian Hospitals' which have been published by Malaysian Ministry of Health in the second (2008) and third (2012) edition.

"Evaluation and long-term management must be performed at a centre with an experienced multidisciplinary team (Paediatric subspecialists in endocrinology, surgery, and/or urology, psychology/ psychiatry, gynaecology, genetics, neonatology, and social work, nursing and medical ethics"

However, in reality, the involvement of non medical experts such as psychology is very minimal and only upon request (Personal communication, May 17, 2010).² All of these situations depict that the multidisciplinary initiatives has not been done effectively and comprehensively. According to Zain (2012), since the issue affects the whole life the affected individuals, the establishment of MDT may become one of the pertinent approaches in the management of SAS and DSD.

In addition to the establishment of MDT in the local hospitals, there was another form of collaboration between JAKIM and MOH in the 55th Malaysian Panel Meeting of *Shari'ah* Studies which was held on February 20, 2006 discussing and justifying the mechanism of sex determination for DSD individuals based on the Islamic perspective (Sajuri, 2006). The result of this collaboration was finally improved the fatwa on the religious regulation of SAS's protocol for DSD individuals.(JAKIM 2014) The result of this discussion had integrated and mutually justified both knowledge efficiently.

Conclusion

Ethical issues in medicine need to be evaluated in various religious perspectives (particularly Islam) and Malaysian socio-cultural setting. The sensitivity of people in particular issues which relate to religious matters and culture must be taken into account in the decision making process. Having said this, those affected newborns later in their adulthood will join the society and therefore they are able to identify themselves according to the norms of the society. MDT should professionally being established and specific protocol about SAS procedure must be outlined and practice in Malaysian hospitals. There were initiatives toward this establishment of MDT as stated in the *Paediatric Protocols for Malaysian Hospitals*, a handbook guideline for Malaysian hospitals which mentioned the role of MDT in evaluating complex ethical issues in medicine as well as meeting between JAKIM and MOH on certain medical issues in formulating fatwas for Muslim community in Malaysia. These initiatives should be further extended in a more serious and professional way, so that this issue can be resolved systematically.

All in all, parents, practitioners and scholars in many disciplines other than the medical and the technical are also important in the management of newborns with DSD. Future consensual statements must include service user, legal, ethical representation, as well as input from experts in sexual development and overall psychological and family functioning. It is inappropriate for the medical professionals to discuss and decide behind the closed doors so as to seal the fate of person with DSD. To this end, a shift from the traditional paternalistic decision-

² Personal communication with Pediatric and Endocrinology Expert, Pediatric Institute, Kuala Lumpur Hospital, Malaysia dated May 17, 2010

making role played by doctors, to one inclusive of multidisciplinary input, and an honouring of the preferences of parents, will help in making this challenging and complex decision. Understanding of the physical and psychological dilemmas of individuals with DSD is very important. Informed consent with complete disclosure of all risks, complications, follow-up and potential for impaired sexual function must be provided to parents with DSD. Parents must be able to access as much information as possible, consult the support groups for further information. Informed consent will also include an awareness of the possibility of non-operative management with psychological support for the child and family. It therefore becomes necessary to refer this individual to a centre that offers a multidisciplinary team which is developed not only on the basis of medical or professional competency but also cultural, social and psychological assessment.

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References:

- AbdelKader, D. (2003). Modernity, the Principles of Public Welfare (*Maslaha*) and the End Goals of Shari'a (*Maqasid*) in Muslim Legal Thought. *Islam and Christian-Muslim Relations*, 14(2), 163-174.
- Al Jurayyan, N.A.M. (2011). Disorders of sex developments: Diagnostic approaches and management options-an Islamic perspectives. *Malaysian Journal of Medical Science*, 18 (3), 4-12.
- Al-Maghribi, H. (2007). Congenital Adrenal Hyperplasia: Problems with Developmental Anomalies of the External Genitalia and Sex Assignment. *Saudi Journal of Kidney Diseases and Transplantation*, 18, 405-13.
- Beh, H.G. & Diamond, M. (2000). An emerging ethical and medical dilemma: Should physicians perform sex assignment surgery on infants with ambiguous genitalia? *Michigan Journal of Gender and Law*, 7(1), 1-65.
- Bird, J. (2005). Outside the Law: Intersex, Medicine and the Discourse of Rights. *Cardozo Journal of Law & Gender*, 12, 65-80.
- Blackless, M., Charuvastra, A., Derryck, A., Fausto-Sterling, A., Lauzanne, K., & Lee, E. (2000). How sexually dimorphic are we? Review and synthesis. *American Journal of Human Biology*, 12(2), 151-166.
- Brain, C. E., Creighton, S. M., Mushtaq, I., Carmichael, P. A., Barnicoat, A., Honour, J. W., Achermann, J. C. et al. (2010). Holistic management of DSD. *Best Practice & Research Clinical Endocrinology & Metabolism*, 24(2), 335-354.

- Budiani, D. (2007). Facilitating organ transplants in Egypt: An analysis of doctor's discourse. *Body & Society*, 13(3), 125-149.
- Butler, J., Guillory, J. & Thomas, K. (2000). *What's Left of Theory? New Work on the Politics of Literary Theory*. New York: Routledge.
- Cahill, L.S. (2003). Bioethics, Theology and Social Change. *The Journal of Religious Ethics*, 31(3), 363-398.
- Catlin, A., Áskelsdóttir, B., Conroy, S., & Rempel, G. (2008). From diagnosis to birth: Parents' experience when expecting a child with congenital anomaly. *Advances in Neonatal Care*, 8(6), 348-354.
- Chase, C. (1998). Surgical process is not the answer to intersexuality. *Journal of Clinical Ethics*, 9, 385-391.
- Chase, C. (1999). Rethinking treatment for ambiguous genitalia. *Pediatric Nursing*, 25, 451-455.
- Cherry, M. J. (2010). Parental authority and pediatric bioethical decision making. *Journal of Medicine and Philosophy*, 35(5), 553-572.
- Creighton, S. M., Minto, C. L., & Steele, S. J. (2001). Objective cosmetic and anatomical outcomes at adolescence of feminising surgery for ambiguous genitalia done in childhood. *The Lancet*, 358(9276), 124-125.
- Creighton, S.M. & Liao, L.M. (2004). Changing attitudes to sex assignment in intersex. *British Journal of Urology International*, 93, 659-664.
- Daar, Abdallah S., and A. Khitamy. (2001). Bioethics for Clinicians: 21. Islamic Bioethics. *Canadian Medical Association Journal*, 164(1), 60-63.
- Diamond M. (1976). Human sexual development: Biological foundation for social development. In F. A. Beach (Ed.). *Human sexuality in four perspectives* (pp. 22-61). Baltimore: The Johns Hopkins Press.
- Diamond, M., & Sigmundson, H. K. (1997). Sex reassignment at birth: Long-term review and clinical implications. *Archives of pediatrics & adolescent medicine*, 151(3), 298-304.
- Dredger, A.D. & Herdon, A.M. (2009). Progress and Politics in the Intersex Rights Movement: Feminist Theory in Action. *A Journal of Lesbian and Gay Studies*, 15(2), 199-224.
- Dreger, A. D. (1998). "Ambiguous Sex"—or Ambivalent Medicine?: Ethical Issues in the Treatment of Intersexuality. *Hastings Center Report*, 28(3), 24-35.
- El-Sherbiny, M. (2013). Disorders of sexual differentiation: II. Diagnosis and treatment. *Arab Journal of Urology*, 11(1), 27-32.
- Fausto-Sterling, A. (2000). *Sexing the body: Gender politics and the construction of sexuality*. NY: Basic Books.

- Göllü G, Yıldız RV, Bingol-Kologlu M, Aydın Yagmurlu, Fedakar Senyücel M, Aktug T, Gökcora H, and Dindar H. (2007) Ambiguous genitalia: an overview of 17 years' experience. *Journal of pediatric surgery*, 42(5), 840-844.
- Greenberg, J.A.(2006). International legal developments protecting the autonomy rights of sexual minorities: who should determine the appropriate treatment for an intersex child? In S.E.Sytsma (Ed.), *Ethics and Intersexuality* (pp.87-102). Springer: Dordrecht.
- Hermer, L.D. (2002). Paradigms Revised: Intersex Children, Bioethics and the Law. *Annals Health Law*, 11, 199.
- Hester, D. (2004). Intersex(es) and Informed Consent: How Physicians' rhetoric constraint choice. *Theoretical medicine*, 25, 21-49.
- Hewitt JK and Warne GL. Management of disorders of sex development. *Pediatric Health* 2009; 3(1), 51-65.
- Houk, C. P., Hughes, I. A., Ahmed, S. F., & Lee, P. A. (2006). Writing Committee for the International Intersex Consensus Conference Participants. Summary of consensus statement on intersex disorders and their management. *International intersex consensus conference. Pediatrics*, 118(2), 753-757.
- Hughes, I. A., Houk, C., Ahmed, S. F., & Lee, P. A. (2006). Consensus statement on management of intersex disorders. *Journal of pediatric urology*, 2(3), 148-162.
- International Albinism Center of the University of Minnesota (IACUM). (2014). <http://www.cbc.umn.edu>. Accessed March 2016.
- Intersex Society of North America . 2014: <http://www.isna.org/faq/frequency>. Accessed on April 2016.
- Inwald, D. (2008). The best interests test at the end of life on PICU: a plea for a family centred approach. *Archives of disease in childhood*, 93(3), 248-250.
- Ismail, H.I.M., Phak, N.H. & Thomas, T. (2012). *Pediatric Protocols for Malaysian Hospitals* (third edition). Kuala Lumpur: Kementerian Kesihatan Malaysia. http://mpaweb.org.my/file_dir/6549703650eae1487f6fb.pdf . ms.263. Accessed April 2014.
- Kamali, M. H. (2003). *Principles of Islamic jurisprudence*. Cambridge, UK: Islamic Texts Society.
- Kass, E., Kogan, S. J., Manley, C., Wacksman, J. A., Klykylo, W. M., Meza, A. & Wiener, E. (1996). Timing of elective surgery on the genitalia of male children with particular reference to the risks, benefits, and psychological effects of surgery and anesthesia. *Pediatrics*, 97(4), 590-594.
- Kessler, S. J. (1998). *Lessons from the Intersexed*. New Jersey: Rutgers University Press.
- Kipnis K, Diamond M. (1998). Pediatrics ethics and the surgical assignment of sex. *Journal of Clinical Ethics*, 9(4), 398-410.
- Kuhnle, U., & Krahl, W. (2002). Impact of culture on sex assignment and gender development in intersex patients. *Perspectives in Biology and Medicine*, 45(1), 85-103.

- Larcher, V. (2005). ABC of adolescence: Consent, competence, and confidentiality. *BMJ: British Medical Journal*, 330(7487), 353-356.
- Mohamed, M.S. & Noor, S.N.M. (2014). Islamic Bioethical Deliberation on the Issue of Newborns with Disorders of Sex Development. *Science and Engineering Ethics*, 1-12. Doi: 10.1007/s11948-014-9534-z.
- National Down Syndrome Society (NDSS). (2014). <http://www.ndss.org> Accessed March 2014.
- Nussbaum, E. (2000). A question of gender. *Discover*, 21(1), 92-99.
- Özbey, H., & Etker, S. (2013). Disorders of sexual development in a cultural context. *Arab Journal of Urology*, 11(1), 33-39.
- Reiner, W. G. (1996). Case study: sex reassignment in a teenage girl. *Journal of the American Academy of Child & Adolescent Psychiatry*, 35(6), 799-803.
- Repetto R. (1972) Son preference and fertility behavior in developing countries. *Studies in Family Planning*, 3(4), 70-76.
- Ringham, K. (2007). Ethical and human rights perspectives on provider's obligation to ensure adolescents' rights to privacy. *Studies in family planning*, 38, 245-32.
- Sajuri, N. (2006). *Sex Determination for Ambiguous Genitalia and Testicular Feminisation Syndrome, 55th Panel Meeting For Syariah Studies of Malaysia, 20 Februari 2006*. Kuala Lumpur: Department of Islamic Development Malaysia.
- Schober, J.M. (1999). Long-term outcomes and changing attitudes to intersexuality. *British Journal of Urology International*, 83(3), 39-50.
- Silber, T.J. (1982). Bioethics: An Interdisciplinary Enterprise. *Journal of Religion and Health*, 21 (1), 21-28.
- Slijper, F. M., & Drop, S. L. (1998). Long-term psychological evaluation of intersex children. *Archives of sexual behavior*, 27(2), 125-144.
- Taha SA. Male pseudohermaphroditism: factors determining the gender of rearing in Saudi Arabia. *Urology* 1994; 43(3): 370-374.
- United Nations (1989). *The Convention of the Rights of the Child*. New York. <http://www2.ohchr.org/english/law/crc.htm>. Accessed on March 2014.
- Veatch, R.M. (1972). Medical Ethics: professional or universal? *Harvard Theological Review*, 65, 531-559.
- Warne, G. L., & Raza, J. 2008. Disorders of sex development (DSDs), their presentation and management in different cultures. *Reviews in Endocrine and Metabolic Disorders*, 9(3), 227-236.
- Washington State Department of Health (WSDOH). Newborn Screening. About one in every 16,000 babies in Washington State is born with CAH. <http://www.doh.wa.gov> (accessed 2 December 2015).

Wilson, B.E. & Reiner, W.G. 1998. Management of Intersex: A Shifting Paradigm. *Journal of Clinical Ethics*, 9, 364-365.

Zain, F.M. (2012). *Approach to Diagnosis and Management of Ambiguous Genitalia in a Newborn Infant*, *Pediatric Endocrine Update*, 11 Februari 2012. Kedah: Hospital Sultanah Bahiyah.

Zainuddin, A. A., Grover, S. R., Shamsuddin, K., & Mahdy, Z. A. (2013). Research on Quality of Life in Female Patients with Congenital Adrenal Hyperplasia and Issues in Developing Nations. *Journal of pediatric and adolescent gynecology*, 26(6), 296-304.

Zainuddin, A. A., Grover, S., Ghani, N. A. A., Rasat, R., Ling, W. L., Mahdy, Z. A., & Siraj, H. H. (2012). Islamic perspectives in counselling muslim patients with disorders of sex development (DSD) with gender-related issues. *International journal of obstetrics and gynaecology*, 119, 133-133.