Ethical and Cultural Issues Relating to Genetic Research and Newborn Screening in the Islamic world

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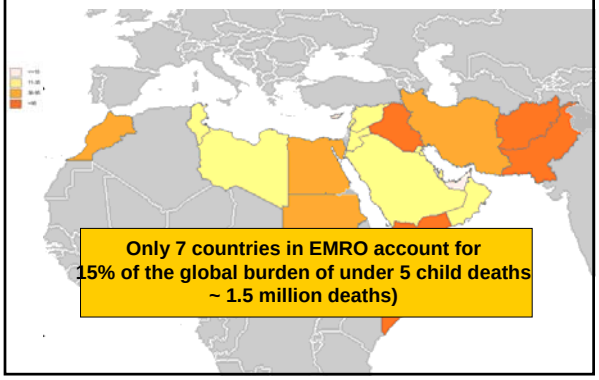
What will I cover?

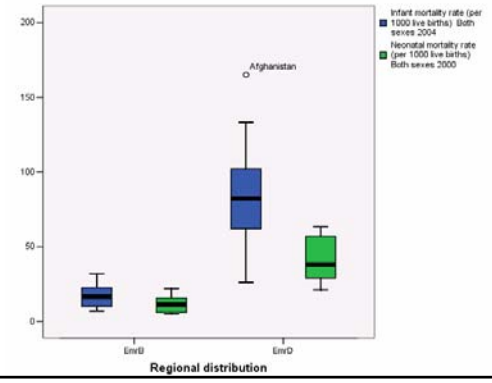
- The context & challenge of genetics and child survival in the Islamic world
- Ethical issues related to genetics research and newborn screening
- Existing guidelines
  - Recent consensus documents
  - Fatwas and injunctions (to be covered in detail by Dr Aida)
- Implications for practice

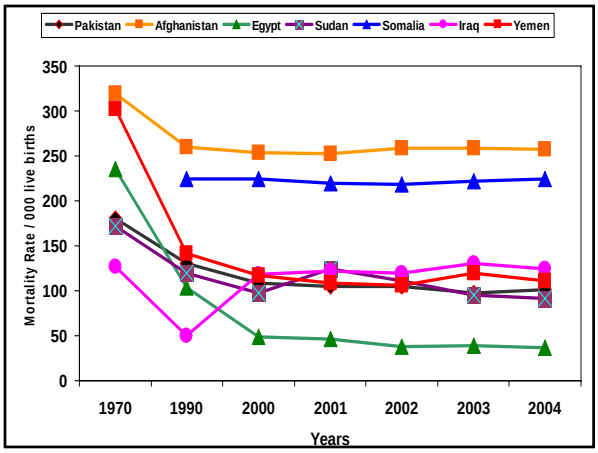
Child Survival in EMRO

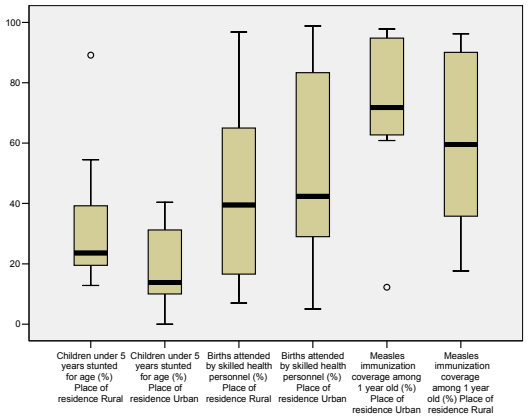


Only 7 countries in EMRO account for 15% of the global burden of under 5 child deaths ~ 1.5 million deaths)

Two EMROs?







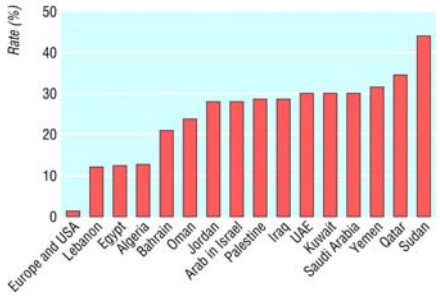
The bottom line

- The Islamic world, especially the EMRO/MENA region has considerable **inequity** in child survival & health outcomes
- While the importance of congenital malformations and inherited disorders is clearly recognized in **transitional countries and the EMRO B countries**, in others health systems are still struggling with basic issues of child deaths due to asphyxia, serious infections (such as pneumonia and diarrhea)
- Public health systems are dysfunctional in many high mortality countries with poor access to known interventions

Growing importance of genetic disorders in the Islamic world

- High consanguinity rates—25-60% of all marriages are consanguineous, and the rate of first cousin marriages is high
- The high prevalence of hemoglobinopathies, glucose-6-phosphate dehydrogenase deficiency, autosomal recessive syndromes, and several metabolic disorders
- The rate of children with Down's syndrome in some Arab countries exceeds the 1.2-1.7 per 1000 typical for industrialized countries. This may be related to the relatively high proportion of births to older mothers in the region (up to 50% of children with Down's syndrome in the region are estimated to be born to mothers aged 40 or over)

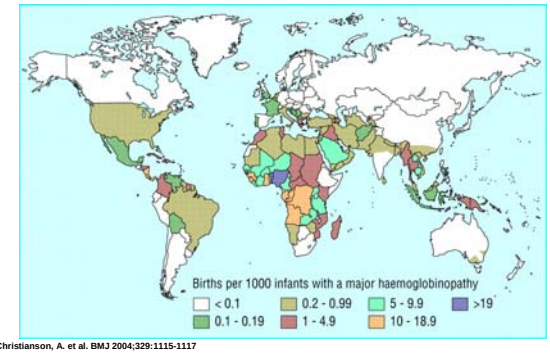
Consanguinity is very common



Average rates of marriages between first cousins among Arabs

Al-Gazali, L. et al. BMJ 2006;333:831-834

So are genetic disorders



Christianson, A. et al. BMJ 2004;329:1115-1117

Hemoglobinopathies in Pakistan

- 5% carriers for β thalassemia
- 0.5-1% carry hemoglobin S or E
- Estimated rate of affected infants is 1.3 per 1000 live births
- 5250 infants with β thalassemia major born annually
- Estimated annual requirements 90,000 units blood and $ 25 million worth of desferrioxamine

Barriers to genetic screening

- The lack of public health measures directed at the prevention of congenital and genetic disorders, with inadequate health care before and during pregnancy, particularly in low income countries
- Services for the prevention and control of genetic disorders are restricted by certain cultural, legal, and religious limitations
- These include cultural fear of families with genetic diseases being stigmatized within their community and the legal restrictions on selective termination of pregnancy of an affected fetus

Other ethical issues

- For screening programs are undertaken at scale, they must fulfill basic criteria of scientific validity, cost-effectiveness and universal access
- If only the rich have access, this will promote inequity and thus public sector screening programs must be coupled with assured availability of services for care
- Where health systems are mixed, these approaches can include public-private partnerships and social support services

Recent issues considered by Islamic scholars and scientists

- Termination of pregnancy for a known abnormality / medical condition
- Fetal sex selection
- Genetic counseling
- Stem cell research
- Cloning

Seminar on Genetics, Genetic Engineering, the Human Genes, and Genetic Treatment - An Islamic Perspective

Organised in association with the Islamic Fiqh Academy, Jeddah, the World Health Organisation Regional Office, Alexandria, and the Islamic Education, Science and Culture Organisation (ISESCO), from

13 to15 October 1998.

The Islamic Jurisprudence Council of the Islamic World League

(Organization of Islamic countries)

Makkah Al-Mukarama
31 October 1998

Decided to

- To use genetic engineering for disease prevention, treatment, or amelioration on the condition that such use do not cause further damage;
- To forbid the use of genetic engineering for evil and criminal uses or what is forbidden religiously;
- To forbid using genetic engineering and its tools to change human personality and responsibility, or interfering with genes to improve the human race;
- To forbid doing any research or therapy of human genes except in extreme need, after critical
- Evaluation of its benefits and dangers and after an official consent of the concerned, respecting the extreme confidentiality of the information and human rights and dignity as dictated by Islamic principles

Inception of life

- The inception of life occurs with the union of a sperm and an ovum forming a zygote which carries the full genetic code of the human race in general and of the particular individual
- From the moment a zygote settles inside a woman's body, it deserves a unanimously recognized degree of respect, and a number of legal stipulations, known to all scholars, apply to it.
- When the zygote arrives at the spirit-breathing stage, the time of which is subject to controversy, being **either forty or 120 days**, the fetus acquires greater sanctity, as all scholars agree, and additional legal stipulations apply to it.

Fetal Sex Selection

- There was an agreement that the Islamic legal viewpoint is that fetal sex selection is unlawful when it is practiced at a national level
- On an individual basis, some of the scholars participating in the seminar believed there was nothing legally wrong with the attempt to fulfill the wish of a married couple to have a boy or a girl through available medical means
- Other scholars believed it is unlawful for fear that one sex might eventually outnumber the other

Termination of pregnancy

- All fiqh scholars strictly and unanimously forbid abortion after the spirit has been "breathed" in i.e. after 120 days
- There is disagreement among scholars on whether there are issues with abortion before 40 days
- Some hold that this is only applicable if there is no threat to the mother's life

The Islamic Jurisprudence Council of the World Islamic League (Organization of Islamic Countries)

10-17 February, 1990 in Makkah Al- Mukarama

Agreed by a majority vote to allow for the option of abortion under certain specific conditions

- The fatwa determined that an abortion may take place only if a committee of specialized, competent physicians has decided the fetus is grossly malformed, and that its life would be a calamity for both the family and itself.
- The malformation must be untreatable, unmanageable and very serious
- The abortion may only be carried out prior to the 120th day of conception (computed from the date of fertilization, not the last menstrual cycle).

The Islamic Jurisprudence Council of the OIC

Jeddah 28 June- 3 July 1997

1. Human Cloning is forbidden in any method that leads to human reproduction.
2. It is forbidden in all cases to introduce a third party into marriage, be it an egg donor, a surrogate womb, a sperm donor, or a cloned cell.
3. It is permissible to use genetic engineering and cloning in the fields of germs, microorganisms, plants, and animals, following legitimate rules which lead to benefits and prevent harm.
4. All Muslim countries are called upon to formulate the necessary legislation to prevent foreign research institutes, organizations and experts from directly or indirectly using Muslim countries for experimentation on human cloning or promoting it.
5. Specialized committees should be set up to look into the ethics of biological research and adopt protocols for study and research in Muslim countries.
6. Biological and bioengineering research institutions (other than cloning research) should be supported and established, according to the Islamic rulings, so that the Muslim world will not be dependent on others in this field.
7. The communication media are called upon to deal with recent scientific advances from an Islamic perspective in a faithful way and avoid employing their services against Islam, aiming to educate the public to be confident before any decision.

Religious injunctions do not mean that all Islamic countries have full consensus on these issues

an example

Table 1 **Votes from countries from the Regional Office for the Eastern Mediterranean (EMRO) and other countries from the Organization of the Islamic Conference (OIC) on the United Nations Declaration on Human Cloning (Resolution adopted by the General Assembly in March 2005) [11]**

In favour		Against		Abstained		Absent	
OIC	EMRO	OIC	EMRO	OIC	EMRO	OIC	EMRO
Albania	Afghanistan	Gabon	–	Algeria	Egypt	Chad	–
Bangladesh	Bahrain			Azerbaijan	Islamic Republic of Iran	Gambia	
Benin	Iraq			Burkina Faso	Jordan	Guinea	
Brunei	Kuwait			Cameroon	Lebanon	Guinea-Bissau	
Comoros	Libyan Arab Jamahiriya			Indonesia	Oman	Kyrgyzstan	
Côte d'Ivoire	Morocco			Malaysia	Pakistan	Mali	
Djibouti	Qatar			Maldives	Somalia	Mauritania	
Guyana	Saudi Arabia			Turkey	Syrian Arab Republic	Mozambique	
Kazakhstan	Sudan				Tunisia	Niger	
Sierra Leone	United Arab Emirates				Yemen	Nigeria	
Suriname						Senegal	
Tajikistan						Togo	
Uganda						Turkmenistan	
Uzbekistan							

Despite issues, progress can be made…

A public health success story from Iran

Iranian national thalassaemia screening programme

Ashraf Samavat, Bernadette Modell

Iran's experience shows that genetic screening can be successful in lower resource countries and also provides some lessons for high resource nations

Table 1 Outcomes in first five years of Iranian thalassaemia prevention programme

	No of couples		Decision of couples (No (%))			Rate/1000	
Year	Tested (1000s)	At risk	Married	Separated	Uncertain	At risk couples	Affected births if no prevention*
1997	353	1 057	486 (46)	473 (45)	98 (9)	3.0	0.75
1998	520	1 534	802 (52)	532 (35)	200 (13)	3.0	0.74
1999	564	2 201	1073 (49)	595 (27)	530 (24)	3.9	0.98
2000	672	2 716	1455 (54)	745 (27)	516 (19)	4.0	1.01
2001	620	2 790	1618 (58)	671 (24)	504 (18)	4.5	1.13
Total	2729	10 298	5431 (53)	3016 (29)	1848 (18)	3.8	0.94

*Based on a simplified assumption of a 1 in 4 risk of an affected child in affected couples and that at risk couples have the same birth rate as the rest of the population.

Impact of screening for Thalassemia in Iran

Table 2 Number of new patients with thalassaemia major registered at Iranian treatment centres during 1998-2002

Year of birth	No of new patients reported	% of expected No without intervention*
1998	480	40
1999	416	35
2000	341	28
2001	206	17
2002	78	7

*Without any intervention about 1200 affected children would be born each year.

Conclusions (1)

- The population in many Islamic countries is characterized by large family size, high maternal and paternal age, and a high level of inbreeding
- Genetic disorders are common in the Middle East & EMRO region and account for a substantial proportion of physical and mental handicap
- Despite lack of public health measures in general, some countries have started cost effective prevention programmes for certain common genetic disorders, such as premarital carrier screening for hemoglobinopathies
- Strategies for the prevention of genetic disorders in this region should include integration of community genetics into the primary healthcare system, education, and strengthening the existing specialized genetic service

Conclusions (2)

- The Islamic injunctions and rulings on prevention/screening for genetic disorders represent an enlightened view keeping the balance between religious edicts, social & family benefits
- The views on termination of pregnancy for known malformations and genetic disorders also permit the procedure in the first 120 days to preserve maternal health
- The biggest challenge is the role of the state and public health context of screening programs