Developing and Evaluating Genetics Education in Developing Countries

Community Genetics distance learning course

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November 6, 2011
# From Research to Practice

## Training Course in Sexual and Reproductive Health Research 2010

**Course modules**

May-October 2010  
6 months distance learning  
June 2011  
Intensive training in WHO Geneva  
organised by  
the Geneva Foundation for Medical Education and Research

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<td>Shyam Thapa (WHO)</td>
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<td>Tomas Allen (WHO)</td>
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<td>Karim Abawi (GFMER)</td>
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<td>Maternal and perinatal health</td>
<td>Mario Merialdi (WHO)</td>
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<td>Sexually transmitted infections, HIV/AIDS</td>
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<td>Luc Montagnier (Luc Montagnier Foundation)</td>
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<td>Sexual health with a special focus on adolescent sexual and reproductive health</td>
<td>Venkatraman Chandra-Mouli (WHO)</td>
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<td>Willy Pasini (GFMER)</td>
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<td>Robert Thomson (GFMER)</td>
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<td>Community genetics</td>
<td>Hanan Hamamy (Geneva University Hospitals)</td>
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[http://www.gfmer.ch/SRH-Course-2010/Community-genetics-course-files.htm](http://www.gfmer.ch/SRH-Course-2010/Community-genetics-course-files.htm)
73 participants from 52 countries completed the community genetics module (54 MD). Module was one month duration (October 2010)
Learning objectives

Educating health care providers in developing countries on:

• What community genetic services can be offered in primary health care settings.
• Taking a genetic family history with pedigree construction.
• Detecting possible genetic risks with referral to specialists.
• Basic ethical principles and techniques of genetic counseling.
Community genetics module Part 1

Introduction to the module of Community Genetics

Introduction to Basic Human Genetics

Unifactorial or Single Gene Disorders

Multifactorial or Polygenic Inheritance

Medical Family History: Tools For Your Practice

National Coalition for Health Professional Education in Genetics
National Society of Genetic Counselors

Cytogenetics Chromosomal Genetics

Sophie Dahoun
Service de Génétique Médicale, HUG
Geneva, Switzerland

Basic Human Genetics: Reproductive Health and Chromosome Abnormalities
Hanan Hamamy
Community genetics module Part 2

Genetic Counseling
Hanan Hamamy

Principles of Population Genetics
Leo P ten Kate, MD, PhD

Ethical issues in medical genetics and genetic services
Summarised by Hanan Hamamy

Basic Concepts in Dysmorphology
Samia Temtamy* & Mona Aglan**

Periconception Care and
Primary prevention of neural-tube defects and other congenital abnormalities by periconceptional folic acid/multivitamin supplementation
Andrew E. Czeizel

Consanguineous marriages
Trends, impact on reproductive health and research priorities
Hanan Hamamy
Community genetics module Part 3

Community Genetics
Hanan Hamamy

Primary prevention of congenital disorders
Hanan Hamamy

Epidemiology, Care and Prevention of Hemoglobinopathies
Nasir Al-Allawi

Rational for birth defect registry, surveillance and monitoring based on the Hungarian experiences
Andrew E. Czeizel

Self-poisoning during pregnancy as a model for teratogenic risk estimation of drugs

Prenatal genetic screening and diagnosis
Hanan Hamamy

Thalassemia Prevention: Screening and Prenatal Diagnostic Approaches
From Research to practice: Training course in Sexual and Reproductive Health Research
Community Genetics
Marina Kleanthous
Molecular Genetics Thalassaemia Department
The Cyprus Institute of Neurology & Genetics
Evaluation

Three sets of questions were sent by emails to participants over a period of one month (October 2010).

The first 2 sets each included 10 MCQs, including questions on pedigree interpretation.

Third set of questions included:

a) 3 case histories
b) a separate set of questions on available and needed community genetics services, and on evaluation of the benefit of the module from the points of view of the participants
c) and..
To review a WHO document and comment on its possible application and adaptation in the participant’s country

Birth defects

Report by the Secretariat

1. The report aims to inform the discussion on birth defects, including definition, epidemiology, burden of disease and interventions for prevention and care, as well as indications of how these interventions might be integrated into existing health services. An earlier version of this report was considered by the Executive Board at its 126th session, following which the Board adopted resolution EB126.R6.

What community genetic services are already present in your country?

Among 34 answer sheets:
In your setting, do you think that you can take a family history, draw a pedigree and decide whether there is a possible genetic disease in a family?

Among 45 answer sheets:
No I can't: Most of the people in my setting don't know the exact causes of death in their previous generations, some families hide the abnormal baby, for most, it is shame to have a malformed or disabled baby.

Yes, I can do it, but not always because many parents do not talk about inherited diseases in their family, educational level is very low and there is fear of stigmatisation.

No, I think that it would be very difficult to carry it out. There are no logistic factors to perform a patient's pedigree in my setting like a suitable place or time to do it.

I can take a family history from most patients but the limitation to drawing a pedigree tree will be the fact that most people do not have histories about parents and much less about grandparents.
Did the community genetic module add to your knowledge in human genetics and community genetics? Please explain your answer?

This module added so much to my knowledge. Is it possible to have practical sessions under supervision in specialized hospital.

Above all it prepares the community to accept these people with deformities unlike attributing it to witchcraft and superstition like they do in African countries.

I would prefer to have more audio presentations explaining some complicated slides.

It sensitised me to introduce this course in the curriculum of reproductive health in our university.
Future prospects

The community Genetics module is part of the 2011 Reproductive health course of the GFMER and will be taken by more than 100 participants during the month of November.

To implement a distance learning course in community genetics targeting health care providers in developing countries with involvement of in country collaborators.
WHO recommendations

Experience and examples from different countries indicate that the most common genetic services at the community level ("minimum package of interventions") are:

Training health professionals in basic concepts of genetics and their application to community genetics services.

Use of family history as an instrument to detect genetic risks.

Conclusions

Training courses and continuous education in the principles of basic genetic counseling and community genetics should be instituted on regular basis for all health care providers.

Distance learning courses in community genetics targeting health care providers in developing countries are beneficial and are needed. They could be strengthened by in country practical sessions and the addition of practical evaluation whenever feasible.

*Genetic education in medical and nursing schools needs to be revised with emphasis on practical applications.*
Developing and Evaluating Genetics Education: Dynamic.....Bidirectional...
Collaborators and Contributors

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