EGYPT

Second Phase of the Study

- **Community:**
  - Situation Analysis Survey
  - Needs Assessment Survey
  - Health Messages

- **Physicians:**
  - Needs Assessment Questionnaire
  - Focus Group Discussion
  - Seminars

- **COV:**
  - Training for surveys implementation
  - Manual for Training

Implementation Phase

(April 1 – Present)

1. Current situation analysis survey:
   - a) Questionnaire preparation
   - b) Training community outreach visitors (COVs) on the utilization of the questionnaire and how to interview the selected families
   - c) Pilot testing on the application of questionnaire and readjusting the questionnaire according to the comments of COVs and results of the pilot.
   - d) Fieldwork: home visits for the application of the questionnaire (531 families)
   - e) Data collection
   - f) Revision of sheets collected after filling the questionnaire
   - g) Double data entry, cleaning and validation
   - h) Data analysis
   - i) Report

Current Situation Analysis Survey Concerning Family Health

❖ Goal

To find out the current health status of the selected families and to recognize the most common genetic problems in order to plan for health education and design health messages suitable for them.

❖ Target Group

- Families from OM Khenan village (n = 531).
- **Sampling:** Systemic random sampling.

Current Situation Analysis Survey Concerning Family Health

- **Implementers:** Community outreach Visitor
- **Training:**
  - Objectives of the survey
  - Communication skills
  - How to apply the questionnaire
  - Instructions for the application of the questionnaire
  - Role play
  - Pre- and post-evaluation test
- **Settings:** Homes of the selected families

- Pilot testing of the questionnaire

  Duration of the field work: 1 month

- COV → 100 families → 4 families/day

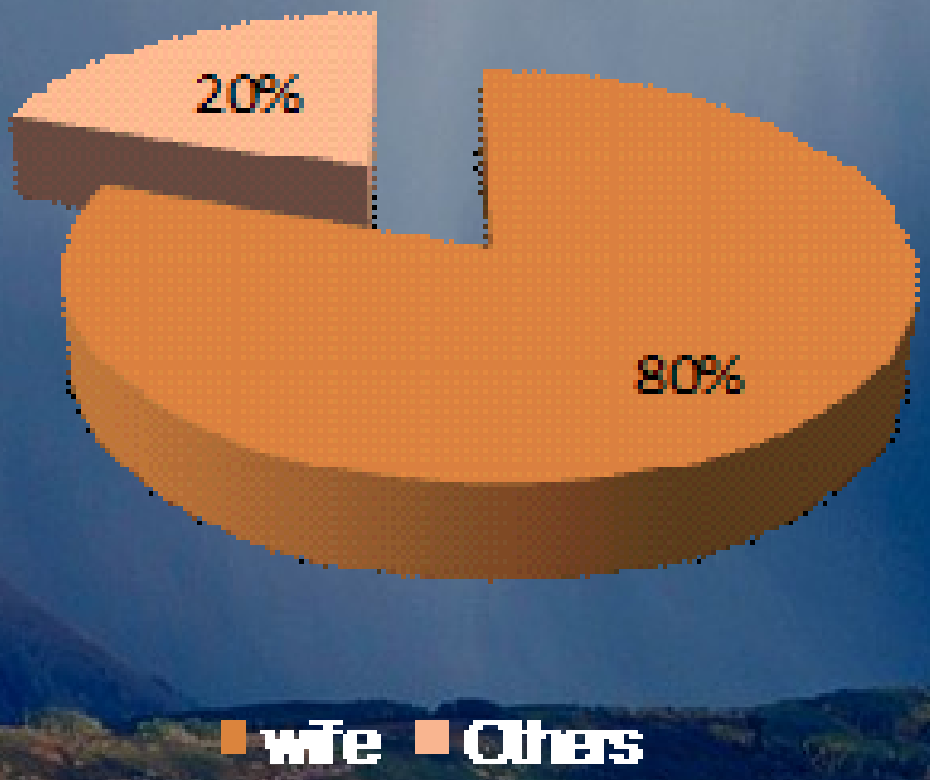
- Supervision and quality check

Current situation questionnaire and instructions for COV

Frequency of Genetic/Congenital Disorders and Different Types of Disabilities Among Children

Abnormalities	%
Congenital anomalies	2.3%
Hearing disabilities	1.9%
Motor disabilities	1.9%
Speech disability	1.7%
Vision disability	3.4%
Mental disability	3%
Down Syndrome	1/700
Congenital heart disease	1.3%
Congenital anaemia	0.3%

Source of Information



Degree of Parents Consanguinity

Physicians' Needs Assessment Survey

Objectives:

1. To determine the physicians' situation as regards their study, training and knowledge in genetics.
2. To recognize their needs concerning genetic knowledge and practice.
3. To verify their satisfaction with the current genetic services in Egypt.
4. To identify current obstacles for the provision of genetic services.

Study Group:

- 50 physicians from Om Khenan village and El-Hawamdya health facilities:
  - 25 general practitioners
  - 22 specialists (Pediatricians, OBGY, family physicians)
  - 3 consultants

Focus Group Discussion for Physicians

❖ Objectives

1) To determine physicians' needs for information concerning clinical genetics, genetic services provided in Egypt and possible ways of referral.
2) To identify the best possible way for community education and suggested education materials.

❖ Target Groups:

1) Ten primary care physicians from Om Khenan PHC unit.
2) Twenty four secondary and tertiary care physciains from Al Hawamdya Hospital, Sugar company medical center and private medical centers.

❖ Open ended questions addressing the following points:

1) The minimum information in clinical genetics required by the physicians to be able to recognize genetic disorders and refer patients to the genetic centers.

2) Available information on genetic services provided in Egypt.

3) Needs for education and possible approaches.

4) Materials needed for genetic health education.

5) Best targets for genetic health education.

❖ Results:

1) The majority of the physicians acknowledged the need for training courses, seminars and workshops in the field of genetics.
2) Some physicians did not have any information on genetic services provided in Egypt.
3) Some physicians needed the address for premarital diagnosis and counseling services together with the list of investigations needed and a price list.

4) They asked for an official referral card to the genetic counseling clinics to be available in their working place.
5) All the physicians asked for a simplified book with photos on how to recognize the most common genetic disorders in Egypt and possible ways of prevention and management.

❖ Results: *{cont.}*

1) They confirmed that the COV is the best candidate for community health education.
2) Some physicians recommended the use of TV spots and newspaper ads for transferring knowledge to the community.
3) Some others suggested social mobilization campaigns with interactive approach with the community.

4) Some physicians demanded that some topics in genetics should be added in the curriculum of secondary school students.
5) Some suggested the youth population as the best target for health education.
6) The majority suggested the mothers to be the best target for genetic health education.

Seminars for Physicians

- **Title:** Genetics and the future of our children: Possible solutions
- **Topics:**
  1) Approach to common genetic problems.
  2) Current genetic services in Egypt.
  3) Genetic and congenital disorders: possible ways of prevention and early intervention.

Seminars for Physicians

- **Target audience:** 25 physicians from El-Hawamdeya city in each seminar.
- **Setting:**
  1) Sugar company medical center.
  2) Physicians syndicate club.

Community Needs Assessment Survey
(June 1 – August 31, 2008)

a) Preparation of the questionnaire & data collection forms

b) COV training

c) Pilot testing

d) Fieldwork: Implementation of the survey through home visits (same families selected before)

e) Data collection, revision, quality control

f) Double data entry, data cleaning and validation

g) Analysis of data

- Needs assessment survey questionnaire was a tool used to identify knowledge, attitude and practice of the community in relation to genetic conditions.

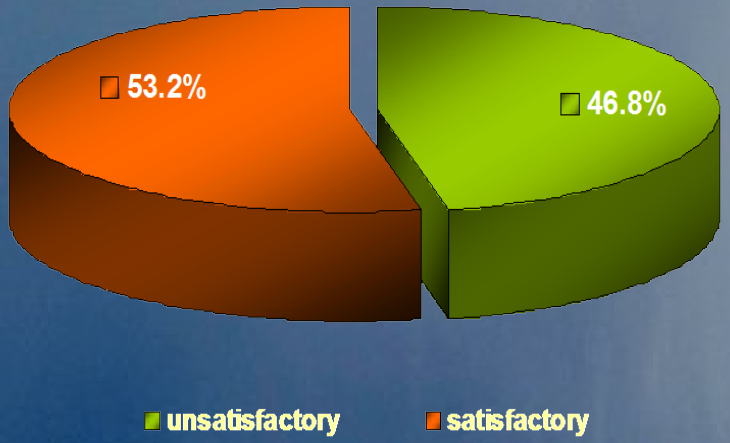
❖ **Importance:**

1) Determining community needs as regards information on genetic diseases, prevention and availability of genetic services.
2) The choice of health education messages.
3) The ways of presenting such messages.
4) The choice of the most suitable target group for health education.
5) Outcome evaluation.

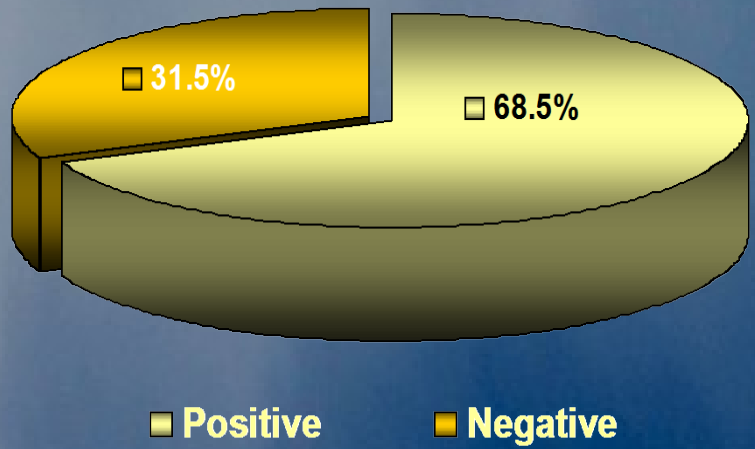
- **Target group:** women of selected families
- **Implementers:** COV
- **Main points in the questionnaire:**
  1) Women's knowledge concerning genetic diseases.
  2) Women's attitude as regards preventive approaches for genetic disorders.
  3) Women's practice during pregnancy for the prevention of genetic and congenital disorders.
  4) Information needs concerning genetic diseases.
  5) Women's needs for the prevention of genetic and congenital disorders.
  6) Women's needs for improving public services.

Highlight on results of the survey:

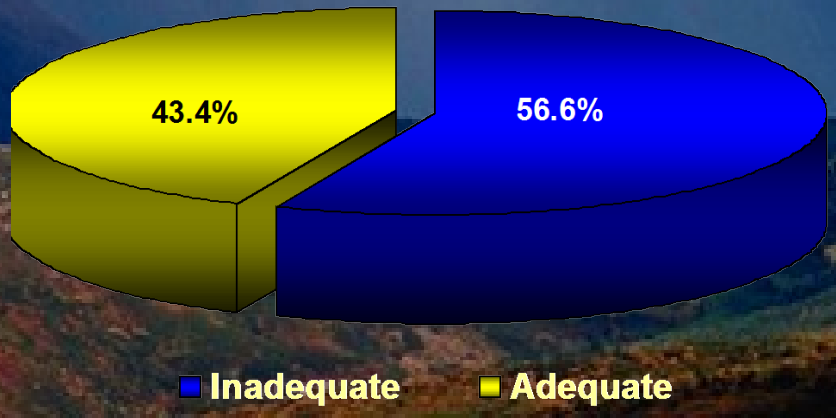
Knowledge about genetic and congenital disorders among women in the study sample (n=501)



Attitude related to prevention of genetic diseases among women in the study sample (n=501)



Practice during pregnancy related to prevention of Genetic and/or congenital disorders among women in the study sample with previous history of pregnancy (n=493)



Highlight on results of the survey:

- 87.2% needed information on genetic diseases.
- 69.1% preferred to receive information immediately before marriage while 29.5% selected school age as the best age for genetic health education.
- Needs for genetic services:
  - Accessibility to genetic services 86.2%.
  - Making premarital examination and genetic counseling mandatory by law 47.1%.
  - Forbidding consanguineous marriage 7.6%.

Highlight on results of the survey: *{cont.}*

- Preferred advisor: husband 61.5%.
- Decision maker in the family: both husband and wife 72%.
- Significant relation between knowledge and:
  - *Age*
  - *Marital status*
  - *Level of education*
- Significant relation between practice and:
  - *Age*
  - *Marital status*
  - *Level of education*
  - *Presence of children*

Relation between women's knowledge, attitudes and practices

	Knowledge				X2 Test	p-value
	Satisfactory (score >=50%)		Unsatisfactory (score <50%)			
	No.	%	No.	%		
Attitude:						
Positive (60%+)	348	78.7	94	21.3	27.19	<0.001*
Negative (<60%)	28	47.5	31	52.5		
Practice:						
Adequate (60%+)	184	86.0	30	14.0	22.62	<0.001*
Inadequate (<60%)	188	67.4	91	32.6		

Statistically significant at p<0.05 (*)

Relation between women's attitudes and practices

	Attitude				X2 Test	p-value
	Positive (score >=60%)		Negative (score <60%)			
	No.	%	No.	%		
Total practice:						
Adequate (60%+)	196	91.6	18	8.4	4.54	0.03*
Inadequate (<60%)	238	85.3	41	14.7		

Statistically significant at p<0.05 (*)

Raising Community Awareness in the Field of Genetics: Simplified Health Messages

الرسائل التثقيفية فى مجال الوراثة البشرية لتوعية المجتمع

Curriculum for training nurses and community outreach visitors on genetic health education

Simplified Manual in the Field of Genetics for Nurses and Community Visitors

CAPABILITY

Contents of the Manual:

1. Definitions and terminology
2. The cell, the chromosome, and the DNA
3. Modes of inheritance
4. Genetic diseases caused by chromosomal abnormalities:
    a) Down syndrome
    b) Turner syndrome
5. Autosomal recessive disorders:
    a) Thalassemia
    b) Phenylketonuria
1. Autosomal dominant disorders:
    a) Achondroplasia

Contents of the Manual: *{cont.}*

1. Sex linked disorders:
    a) G6PD deficiency
    b) Hemophilia
2. Multifactorial inheritance:
    a) Breast cancer
    b) Diabetes
    c) Hypertension
3. Congenital anomalies:
    a) Cleft lip and palate
    b) Neural tube defect
    c) Congenital rubella syndrome
    d) Congenital toxoplasmosis

1. Prevention and early detection of congenital and genetic disorders

What's Next?

1. Testing the prepared materials
2. Training COV and PHC nurses + evaluation of training with a pretest and a post test.
3. Community education through:
   - Home visits
   - Group discussions
   - Seminars held in PHC settings
   - Health education before service provision in health care settings
4. Project outcome evaluation:
   - Questionnaire will be applied on the same target group before and after health education and results will be compared.
   - Gathering information on the number of people attending the corresponding genetic counseling clinic.
   - Ask the physicians on the number of referrals to the clinic / week.


Thank You