



EGYPT

Community Education in Health Aspects of Genetics/ A Capacity Building Project

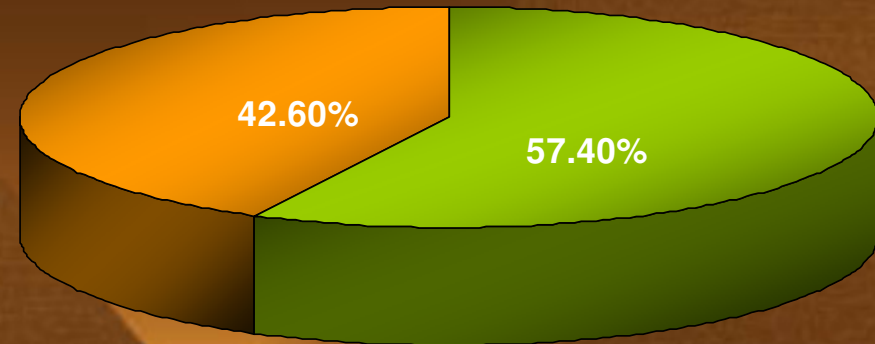


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Introduction



■ Rural ■ Urban

- ❖ Rural community represents 57.4%.
- ❖ Rural population: 45.17 million.
- ❖ Rural villages: 5633.
- ❖ Community health education → one aspect of rural development.

Goal

Genetic Health Education

Target: Rural Community

Sub-objectives:

- ❖ Study the current situation of rural community.
- ❖ Identify needs.
- ❖ Design health education messages.
- ❖ Educate and train COV to provide continuous health education.



Preparation Phase

(January 1st 2008 – March 31st, 2008)

- ❖ Selection of the setting
- ❖ Selection of the target population
- ❖ Selection of health providers
- ❖ Gathering information on the selected community concerning level of education, occupation, resources, Family size and family planning, M/F ratio, Consanguinity, Culture (beliefs, behaviours, attitude, religion)
- ❖ Collecting information on the selected settings concerning educational facilities, health facilities, geographic map and boundaries, urban/rural land



Om-Khenan Village/Giza



Implementation Phase

❖ Community:

- Situation Analysis Survey
- KAP & N. assessment Survey
- Health Messages

❖ Physicians:

- Needs Assessment Questionnaire
- Focus Group Discussion
- Seminars

❖ Community outreach visitors:

- Training for surveys implementation
- Manual for Training



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
- ❖ **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**



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%



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 approach for community education and suggested education materials.



❖ Target Groups:

1. primary care physicians from Om Khenan PHC unit.
2. Secondary and tertiary care physicians from Al Hawamdya Hospital & other specialized centers



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.



Community Needs Assessment Survey

❖ Importance: (KAP)

- 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 health services.



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

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



Raising Community Awareness in the Field of Prevention of Genetic & Congenital Disorders: Simplified Health Messages



Training

❖ **PHC physicians orientation course.**

❖ **COV training course:**

1. Theoretical training

- Manual
- Health messages

2. Practical training

- How to apply the evaluation test
- How to respond to questions
- Role play
- On job training in PHC center

3. Pre and post training evaluation test





Community Health Education

- ❖ **Duration of the field work: 9 weeks**
- ❖ **6 COV → 500 Women**
- ❖ **COV → 84 Women → 2 women/day**
- ❖ **Duration of HE session: 30 – 45 min.**
- ❖ **Supervision and quality check:**
 - **Local → Daily**
 - **Central → Weekly**



Genetic HE Seminars in Om-Khenan PHC Center



Results of Pre and Post Education Test

Knowledge	Time				X ² test	p-value
	Pre (n=488)		Post (n=488)			
	No.	%	No.	%		
■ Satisfactory (50%+)	0	0.0	476	97.5	929	<0.001
■ Unsatisfactory (<50%)	488	100	12	2.5		

Feedback From Clients & Providers

❖ **Clients:**

- 1. Client satisfaction**
- 2. Opinion on the prepared materials**
- 3. More HE in the field of genetics & involvement of other clients.**

❖ **COV:**

- 1. Comparison to other HE activities in other programs in terms of relevance, acceptance and value to the local community.**
- 2. Sustainability**
- 3. Opinion on prepared materials**

Outcome

- ❖ Increase referral from El-Hawamdya city to the genetic counseling clinic
- ❖ 12 were referred from Om-Khenan PHC center:
 - 3 couples for premarital genetic counseling
 - 6 infants and children with Cong. & genetic disorders:
Developmental delay, Down syndrome, multiple congenital anomalies, Thalassemia, MPS.
 - 3 newborns with birth defects:
Down syndrome, skeletal dysplasia, hypospadias



Short Term Plan

❖ Genetic HE Seminars for:

1. PHC physicians
2. Community leaders
3. Local community in Om-Khenan
+ Other villages
4. Secondary school students

❖ Designing other educational materials

Long Term Plan

- ❖ **Extend education to other families and other family members in Om-Khenan village.**
- ❖ **Coordination with other organizations and health authorities to extend the module for community genetic education to other villages.**
- ❖ **Follow-up with target families to detect changes in attitude and practice.**
- ❖ **Sustain networking and sharing deliverables.**
- ❖ **Upgrading and expanding genetic services at the PHC level.**

Thank You



South Africa, March 2009