Capacity Building for the Transfer of Genetic Knowledge into Practice and Prevention

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

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Introduction:

- In Egypt Rural community is bigger than Urban; it represents 57.4% and is growing faster. From the 78 million Egyptians; 45.17 million live in rural areas. There are about 5633 rural villages in the country and they almost have similar infrastructure of governmental services and facilities like health and education.
- Rural development in Egypt has a long history traced back to the 19th century, and recently it has been sought to incorporate the notion of sustainable development. Rural community health education is one aspect of rural development.
- Accordingly, we designed a 2 years capacity building model approach addressing the needs for rural community education in some health aspects of genetics.

Goal:

To provide genetic health education to rural community that should be suitable to their needs. This was achieved through the following:

1. Study the current situation of rural community.
2. Identify needs.
3. Design appropriate health education messages.
4. Educate and train community outreach visitors to provide continuous health education to the selected community.

Preparation phase:

- ❖ 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.

Setting:

The selected setting was Om-Khenan village, it is 4 km^2 in diameter, and is located in Giza governorate in the North of Upper-Egypt in a city called El-Hawamdeya. It is a rural village having similar socio-economic and population characteristics. The infrastructure for governmental services including health and education facilities and services are like those in the majority of the rural villages in Egypt, so it could be considered as a model for other villages and the same health education approach that was applied in the demonstration project could be also applied in many other villages thus serving a large number of the population.

Criteria for selection of the setting:

1. Rural village.
2. Available health facilities.
3. Accessibility of genetic services.
4. Accessible for the team.

Criteria for selection of the target population:

1. All age groups are represented.
2. Unprivileged community.

3. High prevalence of illiteracy.
4. High consanguinity rate.
5. No previous health education in the field of genetics.

Criteria for selection of health education providers:
Trained community outreach visitors (COV) were selected to provide health education to the community. Six COV were selected to do the training; they are University graduates and received a package of training courses in the field of communication, family planning, reproductive health, antenatal care, postnatal care, prevention of infectious and communicable diseases, child healthcare and vaccination and other specialized courses. They are officially employees in the ministry of health.
The COV were chosen because they live in the same community; they are respected and trusted by the community. They are officially allowed to do home visits for family planning and health education for the promotion of primary health care services mainly for the maternal and child health care services.

Demography and target population:

Age Group	1996						2006					
	M		F		Total		M		F		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
0 - 5	2010	49.97	2012	50.03	4022	100.0	2590	50.3	2562	49.7	5152	100.0
>5 - 20	2437	52.97	2163	47.03	4600	100.0	3156	53.0	2776	46.9	5952	100.0
>20 – 40	2428	50.65	2366	49.35	4794	100.0	3181	51.1	3044	48.9	6223	100.0
>40 – 60	1338	54.50	1117	45.50	2455	100.0	1716	54.7	1418	45.3	3134	100.0
> 60 -	434	49.94	435	50.06	869	100.0	533	50.1	531	49.9	1064	100.0
Total	8647	51.65	8093	48.35	16740	100.0	11176	51.9	1035	48.1	21525	100.0

In 2008 the total population of Om-Khenan village was 22,755. The number of live births was 705.
Five hundred families were selected. The technique of sampling was systematic random sampling to insure good representation of the village population.

Occupation:
- Manual workers: 45%
- Farmers: 40%
- Street dwellers: 8%
- No occupation: 7%
- Females:
  - House wives: 68%
  - Farmers: 10%
  - Manual workers: 22%

Educational and health facilities:
Number of schools in the village

Type of School	Public	Private
1) Primary	2	1
2) Preparatory	1	1
3) Secondary	1	-
4) Azhar	-	-

Health facilities:

- Rural health care unit
- Private clinics
- Easy access to:
  1. the general hospital of El-Hawamdeya city
  2. Medical center that belongs to the sugar company in El-Hawamdeya
  3. Genetic counseling clinic in Giza governorate

Important rates:

- Births: 23.6/1000 population
- Deaths: 4.1/1000 population
- Marriages: 25/month
- Consanguinity rate: 32%
- Illiteracy rate: 42%
- Home delivery: 19%
- Vaccination coverage: 98.9%
- Screening coverage: 99.7%
- Use of contraception: 32.4%

Population culture:

- Religion:
  - 85% Muslims
  - 15% Christian
- Beliefs:
  - God and fate
  - Family is sacred
  - Abortion is a sin
- Concept:
  - Provide what's necessary for their children education and marriage

Implementation phase:

- 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

Current situation analysis survey:

- Questionnaire preparation
- Training community outreach visitors (COVs) on the utilization of the questionnaire and how to interview the selected families
- Pilot testing on the application of questionnaire and readjusting the questionnaire according to the comments of COVs and results of the pilot.
- Fieldwork: home visits for the application of the questionnaire (531 families)
- Data collection
- Revision of sheets collected after filling the questionnaire
- Double data entry, cleaning and validation
- Data analysis

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.
- Implementers: Community outreach Visitor
- Settings: Homes of the selected families
- Pilot testing of the questionnaire
- Duration of the field work: 1 month
- COV interviewed 100 families, 4 families/day
- Supervision and quality check by the central team

Results:

Basic data

Data		No	%
Source of questionnaire Information	Wife	415	80%
	Others	107	20%
Religions of contributing families	Muslim	398	85%
	Christian	89	15%
Degree of Parents Consanguinity	None	335	65%
	Close	101	19%
	Less than 2nd degree	83	16%
No of current off-springs per each family	0	32	6
	1	69	13
	2	89	16.8
	3	94	17.7
	4	99	18.7
	5	63	11.8
	>5	82	15.4
	>10	3	0.6
No of dead off-springs per each family	0	378	71.2
	1	85	16
	2	39	7.3
	3	19	3.6
	>3	10	1.9

Maternal data:

No of pregnancy occurred per each mother	0	15	2.9
	1	59	11.3
	2	69	13.2
	3	76	14.6
	4	85	16.3
	5	45	8.6
	>5	154	29.6
	>10	18	3.5
No of abortion occurred to each mother	0	362	68.6
	1	99	18.7
	2	37	7
	3	14	2.7
	4	9	1.7
	5	2	0.4
	>5	5	0.9
No of deliveries occurred per each mother	0	35	6.7
	1	65	12.2
	2	84	15.8
	3	83	15.6
	4	82	15.4
	5	51	9.6
	>5	124	23.4
	>10	7	1.3
Incidental pre-mature deliveries	None	520	98
	Yes	11	2

Data of Common Genetic related Disorders among target families and their relatives:

531 Families	Family Members				Relative Members			
	Alive No	Dead No	Total No	%	Alive	Dead	Total No	%
Congenital anomalies	36	3	39	7.3	86	13	99	18.6
Motor Disabilities	30	2	32	6	92	13	105	19.7
Hearing Disabilities	21	2	23	4.3	46	1	47	8.8
Speech Disabilities	31	-	31	5.8	75	1	76	14.3
Vision Disabilities	64	2	66	12.4	78	7	85	16
Mental Disabilities	41	3	44	8.3	73	8	81	15.2
Down Syndrome	1	1	2	0.4	22	1	23	4.3
Congenital heart Disease	24	4	28	5.2	28	16	44	8.2
Congenital anemia	5	-	5	0.9	20	4	24	4.5
Diabetes (type II)	-	14	14	2.6	291	53	344	65
Bronchial Asthma	53	6	59	11	74	35	109	20.5
Hypertension-Coronary vascular disease	116	9	225	42	305	125	430	81

Community Knowledge, attitude and practice (KAP) assessment survey:

- 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 health services.

Questionnaire for community needs assessment: KAP in relation to genetic conditions

(1) Socio-demographic characteristics:

1	Age	( )
2	Are you currently married	Married ❒ Not married ❒
3	Do you have any children	Yes I have children ❒ No I don't ❒
4	Are you currently married	Yes ❒ No ❒
5	Can you read and write	Illiterate ❒ Read/write ❒ Basic/intermediate ❒ High ❒

(2) Women's' Knowledge about congenital and genetic diseases:

1	Do you know some information about genetic and congenital diseases in children and from where did you get those information	Yes ❒ No ❒ Source/s of information:
2	Do you know what is genetic counseling	Yes ❒ No ❒ If yes, do you know where can you receive such service ----------
3	Did you know that genetic disorders or congenital anomalies can cause motor, learning and cognitive disabilities	Yes ❒ No ❒
4	Do you think that consanguineous marriage can cause genetic diseases in the offspring	Yes ❒ No ❒
5	Do you think that German measles vaccination is useful and why	Yes ❒ No ❒ If yes: for protection from congenital disorders ❒ for other reasons ❒
6	Did you take any vitamins before or during pregnancy and why	Yes ❒ No ❒ If yes: for protection from congenital disorders ❒ for other reasons ❒
7	Did you follow a special diet during pregnancy and why	Yes ❒ No ❒ If yes: for protection from congenital disorders ❒ for other reasons ❒
	Did you avoid any source of infection during pregnancy and why	Yes ❒ No ❒ If yes: for protection from congenital disorders ❒ for other reasons ❒
9	Did you follow proper spacing between pregnancies and why	Yes ❒ No ❒ Reasons:
10	Do you visit family planning clinics	No ❒ Yes ❒ Sometimes ❒ Regularly ❒

(3) Women's attitude in relation to specific situations:

1	Would you advise your daughter to have premarital examination and counseling	Yes ❒ No ❒
2	Would you advise your daughter to marry from the family	Yes ❒ No ❒
3	Would you advise your daughter to space pregnancies	Yes ❒ No ❒
4	What is the appropriate pregnancy spacing period (years)	( )Year
5	What is the appropriate number of offspring	( )
6	Do you think that contraception is against religion	Yes ❒ No ❒
7	Do you think that abortion is against religion	Yes ❒ No ❒
8	What advice would you give if your friend discovered that she is pregnant with a baby who have a serious genetic or congenital disorder	Consult doctor ❒ Follow the opinion of her husband ❒ Do an abortion ❒ Consult the sheikh or priest before deciding for abortion ❒
9	What advice would you give to your friend if she had a child with a serious inherited disorder	Consult a doctor ❒ Get pregnant and do antenatal testing ❒ Get pregnant & hope to have a normal baby ❒ Never get pregnant ❒
10	Do you agree on the belief that says that mentally retarded children including Down syndrome are considered a blessing (Good Omen)	Yes ❒ No ❒
11	Do you agree on the belief that the newborn must be confined to home till he/she is 40 days old	Yes ❒ No ❒

(4) Women's information needs related to genetic diseases:

1	Would you like to know more information about congenital genetic diseases	Yes ❒ No ❒
2	What is the proper age for getting such information	School age ❒ Immediately before marriage ❒ Immediately after marriage ❒ Any age ❒
3	What is the preferred way of getting such information	TV ❒ Newspapers ❒ Radio Seminars ❒ home education through health visitors ❒ Health education brochures, leaflets ❒ Other ways ❒

4	Who would you prefer to get genetic health information from	Specialized male physician ❒ Specialized female physician ❒ Trained nurse/health visitor ❒
5	Preferred location to receive genetic health education	Home ❒ Healthcare setting ❒ Mosques/churches ❒ Clubs ❒ NGO's ❒
6	Would you like your husband to be aware of genetic diseases	Yes ❒ No ❒
7	Would you like your children to be aware of genetic diseases	Yes ❒ No ❒

(5) Women's needs for improving public health services:

1	Reproductive health services	Improve quality of services ❒ Start early for schoolgirls ❒ Good selection of trained physicians to provide the services ❒ Good communication skills of service providers ❒ None ❒
2	Antenatal care services	Improve quality of services ❒ More health education about genetic diseases ❒ Provide Facilities for antenatal testing and screening ❒ Good selection of trained physicians to provide the services ❒ Good communication skills of service providers ❒ None ❒
3	Genetic counseling services	Improve quality of services ❒ More health education about genetic diseases ❒ Start early for schoolgirls ❒ Good selection of trained physicians to provide the services ❒ Good communication skills of service providers ❒ None ❒
4	Prevention and care of genetic diseases	Improve quality of services ❒ Increase number and types of genetic services ❒ More health education about genetic diseases ❒ Start early for schoolgirls ❒ Good selection of trained physicians to provide the services ❒ Good communication skills of service providers ❒ None ❒

(6) Women's needs for prevention of genetic and congenital disorders:

1	For you to start taking preventive measures for genetic and congenital disorders in your family what do you think is needed	Accessibility to genetic services ❒ Increase types and quality of services ❒ Making premarital testing mandatory by law ❒ Raising awareness about possible ways of prevention of genetic

		disorders ❒ Forbidding consanguineous marriages ❒

(7) Influence on women's opinion (preferred advisor):

1	Who is the person that you listen to his/her advice	From inside the family: Husband ❒ Mother ❒ Father ❒ Grand-parents ❒ Mother in law ❒ Other family members ❒ None ❒ From outside the family: Sheikh or priest ❒ Friends ❒ Mayor of the village ❒ others ❒
2	Who is the decision maker in your family	I am ❒ My husband ❒ Both of us ❒ Mother in law ❒ other……

Comments of community outreach visitor:

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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:
  - Needs for accessible and affordable genetic services 86.2%.
  - Making premarital examination and genetic counseling mandatory by law 47.1%.
  - Forbidding consanguineous marriage 7.6%.
- 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, attitude and practice:

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

Relation between women's attitude and practice:

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

(*) Statistically significant at p<0.05

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 (Paediatricians, OBGY, family physicians)
  - 3 consultants

Results:

	Current situation: Knowledge and practice		No	%
1A	Job description	1- Consultants ❒	3	6
		2- GP ❒	25	50
		3 – Specialist ❒	22	44
3A	Experience since graduation	1- < 5 years ❒	20	40
		-2 2- 5-10 years ❒	27	54
		3- > 10 years ❒	3	6
4A	Duration of work in current position	1- < 5 years ❒	20	40
		-2 2- 5-10 years ❒	27	54
		3- > 10 years ❒	3	6
5A	Did you study human genetics?	1-No	5	10
		2-During University study ❒	19	38
		3-Post graduate education ❒	23	46
		4-Training courses in genetics ❒	3	6
		Others		
6A	While patient assessment; when do you consider genetic background?	1-Never, I am dealing with his acute problems	5	10
		2-If the complain is related to inherited disorder	42	84
		3-As a routine step of the examination	3	6
7A	Can you mention 3 of genetic disorders you usually see during practice:	correct answer ❒	42	84
		wrong answer ❒	8	16
8A	How often have you been consulted in genetic related diseases?	1. Never ❒	35	70
		2. Few ❒	10	20
		3. Some Times❒	3	6
		4. frequent ❒	2	4
9A	How often do you give an advice for a premarital situation?	1- Never ❒	35	70
		2- Few ❒	12	24
		3- Some Times❒	3	6
		-4 frequent ❒	-	-
10A	Are you aware about the facilities where genetic services are provided in Egypt? If Yes, mention where you are referring suspected patients?	1-No ❒	-	-
		2-I am not sure ❒	25	50
		3-Yes: to Ministry of health at:	15	30
		4-Yes: to Universities at: National Research Center	10	20
		Yes: to:	-	-
11A	How often do you refer patients for genetic counseling?	1- Never ❒	28	56
		2- Some Times❒	17	34
		3- frequent ❒	5	10

12A	What are the obstacles facing the genetic services provision in Egypt? (You can choose more than one item)	Poor community awareness	43	86
		Customs & beliefs	45	90
		Fear of Stigmatization	10	20
		Community refusal	4	8
		Shortage of specialist	30	60
		Deficient training of health providers	34	68
		Absence of system	47	94
		Health political issues	47	94
		Is not considered a priority compared to other problems	45	90
		Legalization & religious issues	25	50
		Limited resources	40	80
		Others: Please Mention		

Physician satisfaction				
1B	Are you satisfied with current physician's training in genetics	1-Highly satisfied ❒ 2-Satisfied ❒ 3-Neutral ❒ 4-Unsatisfied ❒	- - 3 47 	- - 6 94
2B	Are you satisfied with current community awareness on prevention and treatment of genetic disorders	1-Highly satisfied ❒ 2-Satisfied ❒ 3-Neutral ❒ 4-Unsatisfied ❒	- 3 10 37	- 6 20 74
3B	Are you satisfied with current genetic services provided in Egypt	1-Highly satisfied ❒ 2-Satisfied ❒ 3-Neutral ❒ 4-Unsatisfied ❒	5 10 5 30	10 20 10 60

Do you agree on the following issues:				
1C	Egyptian community currently can accept and is in need for genetic counseling services?	1-Agree ❒ 2-Neutral ❒ 3-Disagree ❒	46 2 2	92 4 4
2C	Teaching human genetics in schools is an effective means for raising community awareness	1-Agree ❒ 2-Neutral ❒ 3-Disagree ❒	48 2 -	96 4 -
3C	Community genetic services should be provided through 1ry health care facilities.	1-Agree ❒ 2-Neutral ❒ 3-Disagree ❒	50 - -	100 - -
4C	Simple and practical health messages directed to community could be an effective method for the prevention of genetic diseases	1-Agree ❒ 2-Neutral ❒ 3-Disagree ❒	50 - -	100 - -
5C	Manual for genetic disorders (Book	1-Agree ❒	44	88

	or CD) is a priority for physicians practice	2-Neutral ❒ 3-Disagree ❒	2 4	4 8
6C	Online education could be an effective method for continuous training in genetics	1-Agree ❒ 2-Neutral ❒ 3-Disagree ❒	25 3 22	50 6 44

Focus group discussion for physicians:

- Objectives:
  - To determine physicians' needs for information concerning clinical genetics, genetic services provided in Egypt and possible ways of referral.
  - To identify the best possible way for community education and suggested education materials.
- Target Groups:
  - Ten primary care physicians from Om Khenan PHC unit.
  - Twenty four secondary and tertiary care physicians from Al Hawamdya Hospital, Sugar company medical centre and private medical centres.
- Open ended questions addressing the following points:
  - The minimum information in clinical genetics required by the physicians to be able to recognize genetic disorders and refer patients to the genetic centres.
  - Available information on genetic services provided in Egypt.
  - Needs for education and possible approaches.
  - Materials needed for genetic health education.
  - Best targets for genetic health education.
- Results:
  - The majority of the physicians acknowledged the need for training courses, seminars and workshops in the field of genetics.
  - Some physicians did not have any information on genetic services provided in Egypt.
  - Some physicians needed the address for premarital diagnosis and counseling services together with the list of investigations needed and a price list.
  - They asked for an official referral card to the genetic counseling clinics to be available in their working place.
  - 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.
  - They confirmed that the COV is the best candidate for community health education.
  - Some physicians recommended the use of TV spots and newspaper ads for transferring knowledge to the community.
  - Some others suggested social mobilization campaigns with interactive approach with the community.
  - Some physicians demanded that some topics in genetics should be added in the curriculum of secondary school students.
  - Some suggested the youth population as the best target for health education.
  - The majority suggested the mothers to be the best target for genetic health education.

Seminars for the physicians:

- Title: Genetics and the future of our children: Possible solutions
- Topics:
  - Approach to common genetic problems.
  - Current genetic services in Egypt.
  - Genetic and congenital disorders: possible ways of prevention and early intervention.
- Target audience: 25 physicians from El-Hawamdeya city in each seminar.
- Setting:
  - Sugar company medical center.
  - Physicians syndicate club.

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

A manual was prepared to provide the COV with simple information in genetics about heredity, some preventable genetic and congenital disorders, and simple practical ways of prevention and intervention so that it could help them in delivering the prepared health messages to the community.

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
6. Autosomal dominant disorders:
   a) Achondroplasia
7. Sex linked disorders:
   a) G6PD deficiency
   b) Hemophilia
8. Multifactorial inheritance:
   a) Breast cancer
   b) Diabetes
   c) Hypertension
9. Congenital anomalies:
   a) Cleft lip and palate
   b) Neural tube defect
   c) Congenital rubella syndrome
   d) Congenital toxoplasmosis
10. Prevention and early detection of congenital and genetic disorders

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

For the purpose of raising community awareness in the field of prevention of genetic and congenital disorders, we have designed illustrative and simple health messages in bright colours cartoon sketches that would be most suitable for that community. Sixteen drawings were designed and gathered in a small educational flip chart on a story of a young couple, starting family life and dreaming of getting healthy children. Through their journey health messages were inserted at each

step; premarital, before getting pregnant, during pregnancy and after delivery. Some information about birth defects, chromosomal and genetic disorders, including the risk of consanguinity and parents' age were also added. Finally, where to seek advices for genetic disorders, starting at primary health care units up to the highly specialized university centers.

COV training:

- Before training the outreach visitors we first performed 2 orientation courses for the PHC physicians in Om-Khenan PHC center and the genetic counseling clinic in Giza, to prepare them for the expected new patients and families from Om-Khenan village who will be coming to the clinics to ask for services. We wanted them to know that credibility is the most important thing in that kind of activities.
- 4 PHC physicians were selected and assigned to do daily supervision on the OV during their HE sessions, so those 4 physicians attended the COV training as well.
- Training course for COV lasted for 3 weeks and it took exactly 16 days. It include theoretical training on the prepared curriculum and then on the health messages. Practical training included role play and on job training. We also trained them on how to apply the evaluation test, and giving them important instructions on how to approach the community and how to respond to questions. A pre and post training test was also performed.

Community education:

- Health education sessions for 500 women through home visits took exactly 42 days within 9 weeks duration, 6 COVs accomplished the fieldwork, each one of them visited about 84 women, 2 women/ day. The session took 30-45 minutes with the application of the pre and post HE evaluation questionnaire it took an extra 10 to 15 minutes.
- Local Supervision on HE sessions was done on a daily basis by the selected 4 PHC physicians and central supervision on a weekly basis by one of us.
- 4 seminars were conducted and were attended by women coming to receive services in the PHC center of Om-Khenan they were gathered and HE using the materials that we prepared was done by 2 COVs and 2 trained nurses.

Pre and post health education evaluation test:

Scoring system:

For the knowledge items, a correct response was scored 1 and the incorrect zero. For each area of knowledge, the scores of the items were summed-up and the total divided by the number of the items, giving a mean score for the part. These scores were converted into a percent score, and means and standard deviations were computed. Knowledge was considered satisfactory if the percent score was 50% or more and unsatisfactory if less than 50%.

Tables 1-8 represent categorical analysis, where each person's score was dichotomized to either "satisfactory (50%+)" or "unsatisfactory (<50%)" according to the total score he/she attained at the pre and posttests. They indicate improvement in most questions and all areas. Overall, table 8 demonstrates that none of the respondents had a satisfactory level of knowledge (none attained a total score of 50% or higher) at the pretest. At the posttest, 97.5% had satisfactory knowledge.

Table 9 is a quantitative comparison of the knowledge scores in each area after being converted into a percent score. For example, in the family planning area, the

mean score of the group at the pretest was 43.19 out of a total score of 100, which means that they attained less than half of the correct maximum score. At the posttest, the score increased to 76.87 out of a total score of 100. This shows that the score improved, and the difference was statistically significant.

Table 1. Pre-post intervention knowledge of participants regarding family planning

Satisfactory knowledge (50%+) about:	Time				X^2 Test	p-value
	Pre (n=488)		Post (n=488)			
	No.	%	No.	%		
Family planning:						
▪ Basis of happy family	31	6.4	395	80.9	551.93	<0.001*
▪ Importance of planning	476	97.5	480	98.4	0.82	0.37
Total for family planning	332	68.0	483	99.0	169.60	<0.001*

Table 2. Pre-post intervention knowledge of participants regarding premarital counseling

Satisfactory knowledge (50%+) about:	Time				X^2 Test	p-value
	Pre (n=488)		Post (n=488)			
	No.	%	No.	%		
Premarital genetic counseling:						
▪ Proper time	6	1.2	7	1.4	0.08	0.78
▪ Procedures	33	6.8	436	89.3	666.62	<0.001*
Total for premarital counseling	2	0.4	308	63.1	442.65	<0.001*

Table 3. Pre-post intervention knowledge of participants regarding consanguinity

Satisfactory knowledge (50%+) about:	Time				X^2 Test	p-value
	Pre (n=488)		Post (n=488)			
	No.	%	No.	%		
Consanguinity:						
▪ Family pedigree	149	30.5	482	98.8	497.15	<0.001*
▪ Consanguineous marriage	178	36.5	481	98.6	428.93	<0.001*
Total for consanguinity	87	17.8	476	97.5	635.17	<0.001*

Table 4. Pre-post intervention knowledge of participants regarding normal pregnancy

Satisfactory knowledge (50%+) about:	Time				X^2 Test	p-value
	Pre (n=488)		Post (n=488)			
	No.	%	No.	%		
Normal pregnancy & antenatal care:						
▪ Planning for pregnancy and preconception counseling	2	0.4	446	91.4	813.40	<0.001*
▪ Folic acid supplementation	25	5.1	481	98.6	853.36	<0.001*
▪ Nutrition in pregnancy	269.	55.1	480	98.4	255.57	<0.001*
▪ Things to avoid	24	4.9	465	95.3	797.06	<0.001*
Total for normal pregnancy	2	0.4	472	96.7	906.07	<0.001*

(*) Statistically significant at p<0.05

Table 5. Pre-post intervention knowledge of participants regarding infectious diseases affecting pregnancy

Satisfactory knowledge (50%+) about:	Time				X^2 Test	p-value
	Pre (n=488)		Post (n=488)			
	No.	%	No.	%		
Infections and pregnancy:						
▪ Rubella and vaccine	2	0.4	401	82.2	672.88	<0.001*
▪ Toxoplasmosis and cats	67	13.7	482	98.8	717.04	<0.001*
▪ Uncooked food risks	59	12.1	479	98.2	730.62	<0.001*
Total for Infections and pregnancy:	6	1.2	482	98.8	928.59	<0.001*

(*) Statistically significant at p<0.05

Table 6. Pre-post intervention knowledge of participants regarding genetic/congenital; diseases in pregnancy

Satisfactory knowledge (50%+) about:	Time				X^2 Test	p-value
	Pre (n=488)		Post (n=488)			
	No.	%	No.	%		
Genetic/congenital diseases/Possible prevention and early intervention:						
▪ Neonatal thyroid screening	21	4.3	482	98.8	871.81	<0.001*
▪ Down syndrome (DS)	6	1.2	485	99.4	940.37	<0.001*
▪ DS risk & early intervention	2	0.4	478	98.0	928.84	<0.001*
▪ Turner syndrome	1	0.2	476	97.5	925.16	<0.001*
▪ Thalassemia	0	0.0	417	85.5	728.07	<0.001*
▪ G6PD deficiency	22	4.5	484	99.2	875.96	<0.001*
▪ Food/drugs restricted in G6PD def.	31	6.4	484	99.2	843.60	<0.001*
Total for genetic/congenital diseases:	0	0.0	482	98.8	952.29	<0.001*

Table 7. Pre-post intervention knowledge of participants regarding genetic counseling

Satisfactory knowledge (50%+) about:	Time				X^2 Test	p-value
	Pre (n=488)		Post (n=488)			
	No.	%	No.	%		
Genetic services:						
▪ Proper time	26	5.3	444	91.0	717.06	<0.001*
▪ Periodic checkup	27	5.5	482	98.8	850.04	<0.001*
▪ Action in case of suspicion	307	62.9	480	98.4	196.38	<0.001*
▪ Service settings	12	2.5	389	79.7	601.62	<0.001*
Total for genetic services	7	1.4	459	94.1	839.02	<0.001*

(*) Statistically significant at p<0.05

Table 8. Total pre-post intervention knowledge of participants

	Time				X^2 Test	p-value
	Pre (n=488)		Post (n=488)			
	No.	%	No.	%		
Total knowledge:						
▪ Satisfactory (50%+)	0	0.0	476	97.5		
▪ Unsatisfactory (<50%)	488	100.0	12	2.5	929.15	<0.001*

(*) Statistically significant at p<0.05

Table 9. Pre-post intervention knowledge scores of participants

Knowledge scores (%)	Time		Mann Whitney Test	p-value
	Pre (n=488)	Post (n=488)		
Family planning:				
Mean	43.19	76.87		
SD	14.78	17.98	534.74	<0.001*
Median	50.00	75.00		
Premarital genetic counseling:				
Mean	20.16	47.70		
SD	8.66	12.27	630.38	<0.001*
Median	25.00	50.00		
Consanguinity:				
Mean	22.54	77.27		
SD	25.85	17.20	601.95	<0.001*
Median	0.00	66.70		
Normal pregnancy:				
Mean	11.66	74.06		
SD	10.98	14.86	740.54	<0.001*
Median	10.00	70.00		
Infections and pregnancy:				
Mean	5.90	82.30		
SD	13.30	14.54	794.99	<0.001*
Median	0.00	80.00		

Genetic/congenital diseases:				
Mean	1.42	74.19		
SD	4.57	16.87	796.12	<0.001*
Median	0.00	69.20		
Genetic services:				
Mean	18.36	75.84		
SD	11.57	18.24	716.79	<0.001*
Median	16.65	77.80		
Total knowledge:				
Mean	13.85	70.21		
SD	5.90	13.12	732.40	<0.001*
Median	13.20	67.90		

(*) Statistically significant at p<0.05

Feedback from clients and 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:
  a. 3 couples for premarital genetic counseling
  b. 6 infants and children with cong. & genetic disorders:
  Developmental delay, Down syndrome, multiple congenital anomalies, Thalassemia, MPS.
  c. 3 newborns with birth defects:
  Down syndrome, skeletal dysplasia, hypospadius

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.