

## EFFECT OF HEALTH EDUCATION ON LEPROSY PATIENTS

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*To assess the knowledge and attitude of leprosy patients before and after health education program. Interventional study (intervention being the health education program). City District Government Leprosy Hospital situated at Gadap Town in the Union Council of Manghopir, Karachi from 1<sup>st</sup> of April till 30<sup>th</sup> of September 2007. Fifty leprosy patients including both males and females were questioned in order to assess their knowledge and attitude towards leprosy. A health education program was conducted and the same patients were re-assessed later for the same variables. Awareness Index Patient was used as an indicator to evaluate the preintervention with the post-intervention results. Forty-eight percent (24/50) stated that it was transmitted by touching. Numbness of hands was noticed by 66% (33/50) of the patients as a first symptom. Leprosy is curable as stated by 98% (49/50) of the patients. Seventy-six percent (38/50) said that leprosy causes deformity. Social life of 92% (46/50) of the patients was affected after the development of leprosy. Fifty four percent (27/50) of the patients lost their job after the disease. Marital life of 80% (40/50) of the patients was affected after the development of leprosy. Fifty percent (25/50) of the leprosy patients were forced to leave the family. Health education program has improved the knowledge of 86% (43/50) of the leprosy patients. Awareness Index Patient for the pre-testing (i.e., before the health education program was conducted) came out to be 5% while after health education program it was 73%. Health education program has improved the knowledge and attitude of the patients regarding leprosy.*

Leprosy or Hansen's disease is a chronic infectious disease caused by *Mycobacterium leprae*.<sup>1</sup> *M. leprae* multiplies very slowly and the incubation period of the disease is about five years. Symptoms can take as long as 20 years to appear.<sup>2</sup> Leprosy mainly affects the skin and nerves; if untreated, there can be progressive and permanent damage to the skin, nerves, limbs and eyes. It is transmitted via droplets, from the nose and mouth, during close and frequent contacts with untreated cases.<sup>3</sup> Until 1940s there was no effective cure for leprosy. However, dapsone was only known weakly bactericidal against *M. leprae* and it was considered necessary for patients to take the drug indefinitely.<sup>4</sup> The search for more effective anti-leprosy drugs to dapsone led to the use of clofazimine and rifampicin in the 1960s and 1970s. Multidrug therapy (MDT) i.e., combining all three drugs was first recommended by a WHO Expert Committee in 1981.<sup>8</sup> These three anti-leprosy drugs are still used in the standard MDT regimens. With MDT, patients are cured within 6-12 months depending upon the type of leprosy.<sup>8</sup> In 1991 World Health Assembly passed a resolution to eliminate leprosy as a public health problem by the year 2000. Elimination of leprosy as a public health problem is defined as a prevalence rate of less than one case per 10,000 persons; the target was achieved on time.

Internationally, approximately 410,000 new cases of leprosy were detected during 2004 as compared to a peak of 804,000 in 1998.<sup>6</sup> At the beginning of 2005, 290,000 cases were undergoing treatment. In 9 countries in Africa, Asia and Latin America leprosy is still considered as a public health problem; these countries account for about 75% of the global disease burden. In 1995, the World Health Organization (WHO) estimated that between two to three million individuals were permanently disabled because of leprosy.<sup>6</sup>

The leprosy situation in Pakistan is fairly accurately known, the disease shows a markedly focal pattern. Prevalence rates vary from less than 1 per 10,000 population (Punjab) to 3.4% in small endemic foci (Bablaqdara in Sawat district, tensil Shangiapar).<sup>7</sup> Certain population groups are heavily infected than others e.g. Ranikot, Gabol Babodi tribe shows a high prevalence, and while Wazir tri-be area is practically free from the disease. Due to the long incubation period, there are still an estimated 15,000-30,000 infected persons in Pakistan. They will develop symptoms in the next 10-20 years. Among the 40,000 diagnosed patients of whom 4,422 are still on chemotherapy, require some kind of rehabilitation services.<sup>7</sup>

The Leprosy Control Program of Pakistan is a professionally vertical, administratively integrated program of the provincial health services. It is aid-

ed by voluntary agencies, two major being Marie Adelaide Leprosy Center based at Karachi and Aid to Leprosy Patients, based at Rawalpindi. All control and related activities are coordinated by the National Leprosy Control Board in which Government and NGOs are equally involved.

Early diagnosis, adequate treatment, and health education are still the most important control measures.<sup>8</sup> Health education is of crucial importance to familiarise the population with the early signs of leprosy and change the old prejudices against the disease.<sup>9</sup> Encouraging self-reporting and early treatment by promoting community awareness has changed the image of leprosy. Patients and their families have to be motivated to cooperate in long-term treatment and in necessary measures for prevention of deformity, better education and improved housing. Better standard of education, and improved housing would undoubtedly have a noticeable effect on the prevalence, as shown by the decline of leprosy in Europe parallel to improved living conditions, even before any effective drug was known.<sup>10</sup>

Leprosy patients remain unaware regarding the significance of early symptoms, the importance of early diagnosis and prompt treatment. When leprosy is diagnosed patients are subjected to the traditional fears of the social stigma associated with the disease. Our aim was to explore the effect of health education on the knowledge and attitude of patients regarding leprosy. We also provided information regarding the foot care and importance of compliance in treatment.

Objectives of our study were to assess the knowledge and attitude of patients before and after health education and to deliver health education program.

## PATIENTS AND METHODS

This interventional study was carried out in City District Government Leprosy Hospital situated at Gadap Town in the Union Council of Manghopir, Karachi during the period of 1<sup>st</sup> April till 30<sup>th</sup> of September 2007. A structured questionnaire was prepared in English and later translated in simple Urdu. It was pre-tested for better clarity on three 4<sup>th</sup> year students. Those patients who gave verbal consent were enrolled in the study. Names and addresses of the eligible candidates were kept confidential. Variables on demographic profile were age, gender, occupation and marital status. Variable regarding knowledge of the patients about leprosy were mode of transmission, early symptom, communicability, curability and any deformity caused by leprosy. Variables related to attitude included different problems experienced by the patients personally, while living with the fa-

mily and while at work.

Fifty leprosy patients were selected by non-probability convenient sampling regardless of their age and sex. They were introduced as study participants. However the patients already had health education regarding leprosy, were excluded. A health education program was conducted on study participants. This health education program was treated as an intervention. Same group of patients were given the same questionnaire to fill after 2-3 months. Frequencies of different variables regarding the knowledge and attitude towards leprosy were calculated. Awareness Index Patient was used as an indicator to evaluate the results of pre-testing (pre-intervention) with post-testing (post-intervention) results.

Awareness Index Patient consisting of variables of knowledge and attitude. This indicator is used in the Leprosy Center, Manghopir, as suggested by W.H.O. (World Health Organization).<sup>4</sup> In Awareness Index Patient 5 variables (given weightage of number 1 for each variable) are considered for assessing the knowledge of the patients regarding leprosy. Those variables are the cause of disease, early signs, curability, deformity, communicability and number for attitude is given. All the different variables, are set for assessing the attitude, were cumulatively considered as 1. The responses (in the form of right and wrong) are considered in the numerator. If a patient gives right answer to any variable he is given a score of 1 whereas for the wrong answer he is given 0. Finally the total number of numerator is divided by 6.

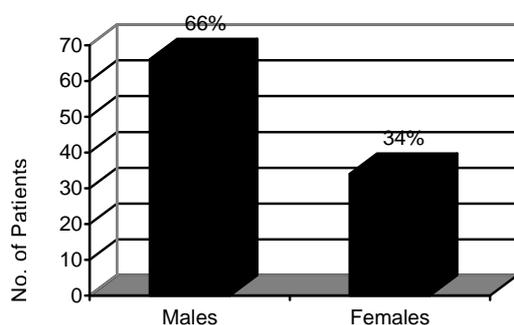
If the total score of this indicator for a patient varies between 0-3 (0-50%) then that patient needs health education and if the score is above 3 (>50%) then no intervention is required. Only the frequencies of different variables of post-test and the Awareness Index Patient of pre-test and post-test are shown in the article.

## RESULT

In demographic profile of leprosy patients, 66% were males (33/50) and 34% were females (17/50). Regarding the marital status, 18% were unmarried (9/50), 78% were married (39/50) and 4% (2/50) were widows.

As regards the different occupations adopted by the leprosy patients. 16% percent (8/50) started working inside the leprosy center as fruit sellers, vegetable sellers or as cobblers while 10% (5/50) started working as welfare workers inside the leprosy center. Thirty four percent (17/50) became jobless when they contracted leprosy.

The variables regarding the knowledge of the patients about leprosy are detailed in table 1. Forty-eight percent (24/50) stated that it is transmit-



**Fig. 1:** Showing the sex and marital status of Leprosy patients.



**Fig. 2:** Showing different occupations adopted by the Leprosy-patients.

ted by touching. Twenty six percent (13/50) thought it was divine in origin while 4% (2/50) considered it as hereditary. Sixty six percent (33/50) of the patients noticed numbness of hands as an early symptom of leprosy while 20% (10/50) noticed a discoloured skin patch. There is no vertical transmission of the disease as answered by 94% (47/50). Forty percent (35/50) of the leprosy patients did not have proper knowledge about leprosy before the occurrence of disease in them. Forty-six percent (23/50) said that it is a communicable disease. Leprosy is curable stated by 46% (23/50) of the patients. Seventy-six percent (38/50) said that leprosy causes deformity.

The variables regarding the attitude of the patient and the community towards leprosy are shown in table 2. Social life of 92% (46/50) of the patients is affected after the development of leprosy. Fifty four percent (27/50) of the patients lost their jobs after the contracting disease. Hesitation to talk to people was reported by 40% (20/50) of patients. Other social problems were, isolation of the patients in the form of hesitation to go the people and attending social gatherings was reported by 70% (35/50) of patients. Marital life of 80%

(40/50) was affected after the development of leprosy. Family members do not eat with the patients as reported by 90% (45/50) of patients. Fifty percent (45/50) leprosy patients were forced to leave the family. Health education program had improved the knowledge of 86% (43/50) of leprosy patients.

**Table 1:** Knowledge of patients regarding Leprosy (after health education program).

Variables	Responses	Frequency (n = 50)	Percentage
Transmission of leprosy	Touching	24	48
	Sneezing	4	8
	Food stuff	5	10
	Hereditary	2	4
	Divine	13	26
	Unknown	2	4
Early symptom noticed by the patient	Numbness of hand	33	66
	Discolored skin patch	10	20
	Auto-amputation	3	6
	Deformed nasal bridge	2	4
	Thickened ear lobes	2	4
Communicable disease	Yes	23	46
	No	27	54
Is leprosy curable?	Yes	49	98
	No	1	2
Leprosy deformed any body parts	Yes	38	76
	No	12	24
Numb skin patch developed	Yes	14	28
	No	36	72
Vertical transmission	Yes	3	6
	No	47	94
Transmission through breast feeding	Yes	3	6
	No	47	94
Knowledge of leprosy before disease	Yes	15	30
	No	35	70

Awareness Index Patients for the pre-testing i.e., before the health education program was con-

ducted came out to be 5% while after health education program it was 73%.

**Table 2:** Attitude of patients and community towards leprosy (after health education program).

Variables	Responses	Frequency (n = 50)	Percentage
Leprosy affected social life	Yes	46	92
	No	4	8
Fired from the job	Yes	27	54
	No	23	46
Hesitation to talk with the people	Yes	20	40
	No	30	60
Not to go near to others	Yes	35	70
	No	15	30
Hesitation to attend social gatherings	Yes	35	70
	No	15	30
Leprosy affected marital life	Yes	40	80
	No	10	20
Refusal to eat with the patient	Yes	45	90
	No	5	10
Forced to leave the family	Yes	25	50
	No	25	50
Satisfaction of the patient with the treatment	Yes	49	98
	No	1	2
Health education program has improved the knowledge regarding leprosy	Yes	43	86
	No	7	14

## DISCUSSION

Leprosy control measures are carried out according to WHO guidelines, which are case finding, case holding and health education.<sup>11</sup> Health education is of crucial importance to familiarise the population with the earliest signs of leprosy and change the old prejudices against the disease.<sup>11</sup>

Patients and their families have to be motivated to co-operate in the lengthy treatment and necessary measures against the prevention of deformity. The biggest remaining barrier to eliminate the disease are; ignorance and stigma, people do not know that effective drugs are available and people are afraid to seek treatment.

In India, where 60% of leprosy patients live,

leprosy has been seen as either hereditary or (as written in Hindu scriptures) a curse from God. Same results were obtained from our study where 4% of the patients quoted that the disease is hereditary while 26% considered it to be of divine origin. In our study it was revealed that family members did not eat food with the patients while in 50% of the cases the patients were forced to leave the family. Same results were revealed from the study done in India where people who have the disease have not been able to marry, nor were allowed to live with the family. For this reason people have typically hidden the early symptoms as long as they possibly can, resulting in inevitable deformity and misery.

The World Health Organization commissioned the BBC World Service Trust to conduct a national radio and television leprosy awareness campaign in Brazil, in partnership with the Brazilian Ministry of Health, Morhan, Pastoralda Crianca and Brazil's major broadcasters. The purpose of the campaign was to raise awareness about leprosy (called Hensenias disease in Brazil), its symptoms and treatment. The campaign emphasized three key messages:

1. How to recognize leprosy symptoms.
2. Leprosy can be treated and cured.
3. A person on treatment is not contagious, and can continue to have a normal life while being treated.<sup>12</sup>

The campaign had a positive effect on perception about leprosy treatment. Correct beliefs regarding leprosy treatment (leprosy is curable, believes that a person being treated is not contagious, believes a person being treated can live a normal life) and tolerance of people being treated (would sit next to person on receiving treatment in a public place) are at approximately 30% higher levels among those exposed to the campaign, compared to those not exposed.<sup>11</sup> Similar results were obtained from our study as well.

"Skin blemishes, lack of sensitivity, numbness may be a sign of leprosy" was recalled by 41% of people exposed to the campaign. In our study numbness may be a sign of leprosy was answered by 66% of the patients who were exposed to health education programme.

"Leprosy can be cured was answered by nearly 17%. "A person being treated for Hensenias can continue to have a normal life" answered by 4.1%. "Hensenias ceases to be contagious after the first treatment" answered by 3.8%. The evaluation shows that leprosy awareness campaign had a significant and positive impact upon knowledge, attitude and information-seeking about leprosy.<sup>12</sup> These results are close to our research findings after the intervention of health education program. The ca-

mpaign had a significant and positive impact upon awareness of leprosy and its symptoms. Levels of hanseniasis awareness and knowledge of specific symptoms are approximately 30% higher among those exposed to the campaign, compared to those not exposed.<sup>12</sup> Similarly, Awareness Index Patient in our study for the pre-testing i.e., before the health education program was 5% while after health education program it was 73%.

Main emphasis should be on health education and early diagnosis. Patients hide their disease. Professional workers are still reluctant to work in this field. Public still fears from those cured from the disease. Segregations also occur so patients prefer to live with the people like themselves in segregated institutions called Leprosaria.<sup>9</sup>

There is a need to promote research in designing more effective medicines and vaccine against leprosy and improving community's response against the disease. Early diagnoses is very important in order to prevent permanent deformities, but this is possible only when patients and their families do not hide the problem due to social stigma. Patients should be rehabilitated in the hospitals so they could earn their living.

Life normalisation and social integration will come only if we place emphasis on both the medical side and as well as social side of the disease on changing the person with the disease and the society in which he lives. It is the duty of the higher authorities, organizations, philanthropist and mass media to continue and enhance efforts in the battle against leprosy.

Hence it is recommended that;

1. Health education program should be conducted in leprosy centers for the patients in order to alleviate their fear about the diseases and tell them about general cleanliness, proper disposal of sputum, and the importance of compliance in the control of leprosy.
2. Health education programs should also be conducted for the general public in order to improve their attitude towards the patients.
3. Media should be used to make aware the general public about different modes of spread of infection, early presentation of leprosy etc.
4. Seminars, symposia and public awareness pro-

grammes on leprosy should be arranged.

5. More field centers, social and rehabilitation centers should be established in the country.
6. Leprosy patients once become non-infectious should be given special jobs.

It is **concluded** that leprosy is considered as a social stigma. Leprosy is a disabling disease that affects the patient physically as well as mentally. People of our society do not have proper knowledge regarding leprosy that is why their attitude is not fair with the patient.

Health education program had a significant and positive impact upon knowledge and attitude of the patients regarding leprosy.

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