



NHRC Library  
Accession No. 53  
Call No. ....



ACKNOWLEDGEMENT

2001

**THE IMPACT OF PSORIASIS IN THE PSYCHO-SOCIAL WELL BEING OF CHRONIC PSORIATIC PATIENTS AND THEIR FAMILY MEMBERS: A COMMUNITY BASED STUDY**

The final report submitted to NHRC by  
DR. DWARIKA PRASAD SHRESTHA (Principal investigator)  
ASST. PROFESSOR  
DEPT. OF DERMATOLOGY  
INSTITUTE OF MEDICINE  
and  
DR. KAMAL GYAWALI (Co Investigator)  
ASSOCIATE PROFESSOR  
DEPT. OF PHARMACOLOGY  
INSTITUTE OF MEDICINE

**PROJECT ADVISER  
PROF. GOPAL P. ACHARYA  
HEAD OF DEPARTMENT  
DEPT. OF MEDICINE  
INSTITUTE OF MEDICINE**

## ACKNOWLEDGEMENT

First I would like to thank Prof. Gopal P. Acharya and the NHRC for the grant, which has made this research possible.

I would like to thank Prof. Ramesh Kant Adhikari, then the campus chief of Maharajgunj Campus for consenting and encouraging the research on behalf of the Institute of Medicine.

My gratitude also goes to Dr. Ashish Upadhyay and Miss Sulochana Kayastha, who have helped me with their hard work and dynamism.

Lastly I thank the VDC chairmans of Chapali, Budhanilkantha and Talku, Lamagaon of Pharping.

Contents:

Summary	4
Introduction	5
Objectives	7
Methodology	8
Criteria for the selection of the patients for the interview	8
Period of the study	8
Recruitment and training of the research assistants	8
In depth interviews	9
Interview checklist	10
Community interactive programmes	11
Group interviews	11
Results	12
Index tree	12
Individual interviews	15
Psycho-social impact in patients	15
Psycho-social impact in family members	18
Group interviews	18
Psycho-social impact in patients and family members	18
Discussion	19
Patient/Family demographic format	21
Patient clinical datas	22
Tables of the demographic datas	23
References	27

## *Summary*

Psoriasis is a common and chronic dermatopathy with significant impact in the physical activities and the psychosocial well being of the patients.

The objective of the study is to assess the psycho-social impact of psoriasis in chronic psoriatic patients and their family members.

The patients for the interview were selected from psoriatic patients, with severe disease of at least 5yrs duration, from those attending the TUTH and B & B Hospital, and those diagnosed to have psoriasis in the community interactive programmes conducted during the study. Along with the patients, some family members were also identified. Altogether 21 patients and 9 family members were interviewed.

Most patients and family members are convinced that it is not a contagious disease. Community members mistaken it for leprosy and think that it is contagious. Patients tend to hide the disease and they worry that it will come in the visible places and others (community members) will see it. Spouses, family members and friends are in general supportive. Community members discriminate against the patients. This is the main reason of sadness and fear in the patients. Itching and scaling give some problem. They fear most the reactions of the community members and the consequent acts of discrimination. The patients are very sad and worry because the disease doesn't get cured, it may be related to some other serious disease and it may be transmitted to children.

In conclusion social stigmatization is the main problem due to psoriasis and this in turn is responsible for sadness, fear and worry in the patients life.

## *Introduction*

Psoriasis is a chronic inflammatory disease, which mainly affects the skin, nails and articulations. It is almost universal in occurrence and the prevalence ranges from nearly 3% for residents of the Faroe Islands and Denmark to 0% for native South American Indians (1) with marked geographical and racial variation. It is one of the most common skin diseases in Nepal with a prevalence of 3.6% in the Dermatology Department of the Teaching Hospital.(2)The etiopathogenesis is still unclear. A genetic pre-disposition seems to be necessary. The disease is more common among monozygotic twins, kins and there is high association with some HLA antigens-B13, -B17, -Cw6. Environmental factors play equally important role as precipitating/aggravating factors. Cold, infections, stress and drugs are the common triggers. Both males and females are equally affected. The peak age at onset is in the second decade. The most common clinical types are psoriasis vulgaris, guttate psoriasis, erythrodermic and pustular psoriasis. Psoriasis vulgaris, comprises more than 80% of psoriasis cases and presents with salmon red desquamative plaques on the scalp, elbows, knees and extensor surfaces of the arms and legs. In the guttate type reddish scaly papules are distributed all over the body. Erythrodermic form characterized by generalized erythrodermia and pustular type by sheets of minute pustules are the severe manifestations which can be life threatening. In about 7-17% of cases there is psoriatic arthritis, involving mainly the distal interphalangeal joints. The disease progresses with waxing and waning phases, and in most cases lasts for the whole life.

Until now there is no effective cure for this disease. Like any other health problem, due to lack of health facilities in Nepal, psoriasis is either not treated or under treated. The therapies currently available are very costly. It is unaffordable to most, as the treatment has to go for years, if not the whole life. Due to the necessity of prolonged treatment, frequent relapses and high cost, there is very poor compliance with the treatment. In one study, the rate of non compliance with the treatment regime was around 39% (3). Many patients with psoriasis, particularly those with severe disease, are frustrated with the management of their disease and the perceived ineffectiveness of their therapies (4).

Although psoriasis is not a common cause of death, it's prolonged morbidity is highly disabling. Living with psoriasis, like other chronic diseases, has implications on the various dimensions of life. It affects the psycho-social well being, work and the daily activities. Krueger et al (4), in a large questionnaire survey, found that individuals with psoriasis believe that the disease has a profound emotional and social as well as physical impact on their quality of life.

The skin plays an integral role as an organ of communication throughout life and greatly affects an individual's body image and self-esteem. In contrast to other diseases, skin diseases are visible and disturbs the body image. This is true with all skin diseases, namely Hansen's disease, xeroderma pigmentosum, neurofibromatosis,

psoriasis, vitiligo, moles, birth marks, acne and scars, Due to this undesirable look, the patient feels different from others which may lead to a sense of inferiority complex. In the society, there is a tendency to reject these individuals mainly due to the fear of contagiousness. This limits or makes difficult social interactions for the skin patients. Hence social stigmatization is an important problem in skin diseases. In the case of psoriasis the visible lesions disturb the normal appearance of the patient and this distress regarding the observable symptoms, has numerous and severe psycho-social and behavioral consequences. He or she is embarrassed, insecure, depressed, not to talk about problems with social relations. There is a lot of apprehension about the people's reaction to the disease. Fortune et al (5) have shown that stress resulting from anticipating other people's reactions to their psoriasis contributed more to the variance in patient's disability than any other medical or health status variable. In a study conducted by Gupta & Gupta (6), psoriatic inpatients had the highest rate of suicidal tendency among disfiguring skin diseases.

Regarding the local beliefs and explanatory models of psoriasis very little information is available. In Nepal psoriasis is frequently mistaken for leprosy, with the imaginable social consequences. There is great fear that the disease can be contagious. One of the first questions that the patient and family members ask is, if it transmits to other family members. In our society, like many other skin diseases, patients link psoriasis with presumed impurities in the blood.

The most frequent symptoms experienced by patients in a survey by Krueger et al (4) were scaling (94%) and itching (79%). In the more severe forms, there are difficulties in all types of physical activities. Patients have difficulty in using hands, feet and there is general body discomfort. This limits in doing all kinds of jobs and other activities. There is clear influence in the selection of the job and productivity. In a study by Finley and Coles (7), of the 150 working patients 59.3% had lost a mean of 26 days of work in the previous year because of their psoriasis and of the 180 not working 33.9% attributed not working to their psoriasis.

Above all, the long or life long duration of the disease, requiring continuous care is very frustrating and financially distressing for the patients. Psoriatic patients report poorer health related quality of life than the general population.(8) In conclusion psoriasis negatively affects the various life domains - psycho-social, professional and daily activities, thereby significantly lowers the patient's quality of life.

While much attention has been dedicated towards the clinical signs and symptoms, less has been done to understand the implications that the disease has in the psychological and social spheres of the patient's life. No such study has yet been done in Nepal. This study aims to assess, from the point of view of the patients, family members and the community members, the psychological and social impact of psoriasis on the life of the patient and the family members. For the effective management of the disease, interventions should be programmed towards these hidden aspects of psoriasis-patient interrelations and implications in the family members, along with the therapy of the physical signs and symptoms.

## *Objectives*

### *General Objective*

To study the psycho-social impact of psoriasis in chronic psoriatic patients and their family members

### *Specific Objectives*

- To assess the psychological impact of psoriasis in chronic psoriatic patients and their family members
- To assess the social impact of psoriasis in chronic psoriatic patients and their family members
- To explore local beliefs and explanatory models of psoriasis
- To explore factors which help patients in coping with psoriasis

## *Methodology*

### *Criteria for the selection of the patients for interview*

The patients with psoriasis were selected from:

- psoriatic patients who came for follow up in TUTH or B&B hospital;
- new psoriatic patients identified in the TUTH or B&B hospital;
- new psoriatic patients identified in the community interactive programmes.

The criteria for the enrollment of psoriatic patients in the study were that the disease must be severe and of at least 5 years duration. Severe psoriasis was defined by one of the following characteristics – psoriasis on more than 10% of body surface, erythrodermic psoriasis, generalized pustular psoriasis, disease that cause difficulty in at least 3 of the 4 following activities: standing, use of hands, sitting long periods of time, sleeping and psoriasis that has been treated with PUVA and/or methotrexate.

Patients must be residents of Kathmandu valley.

### *Period of the study*

The duration of the study was of 6 months from October 2001 to March 2002.

### *Recruitment and the training of the research assistants (RAs)*

In the second week of October 2 research assistants were identified and recruited. They were Dr. Ashish Upadhyay, a young intern who has just completed his MBBS, and Miss Sulochana Kayastha, a student in the last year of Master's course in social anthropology.



Subsequently a thorough orientation was given to the research assistants. First it was necessary that the RAs were familiar with the skin disease – psoriasis. The clinico-epidemiological features of the disease was explained in detail. For the better knowledge of the disease, RAs were also shown psoriatic patients. Then the various aspects of the study, in particular the objectives, the rationale, and the methodology were explained in detail. The main objectives of the study, the psychological and social impact in the life of the patients and their family members were underlined.

A brief introduction regarding qualitative research, the validity and reliability of qualitative research, the difference between qualitative and quantitative research and various methods in qualitative research was given.

A very detailed presentation of the in-depth interview and its various steps was made. The checklist for the in-depth interview was discussed. Some interviews were taken using role models and the way of taking interviews was discussed again and again with the objective that the interview resembles an informal conversation with a purpose. There was a brief field training including a sample interview.

### *In depth interviews*

Altogether 30 patients and family members, male-12 and female-18, from 15 – 70yrs of age were enrolled in the study. Among them 21 were patients and 9 family members. In the selection of the patients variability in regard to sex, age, profession, province were taken in consideration. The demographic and clinical data were recorded in a prepared format (Tab. 1 & 2). The various demographic data of the patients interviewed are given in the tables from 3 -11.

In all the patients and family members in-depth interviews were taken individually. A check list was used for the interview. All the interviews were taken in the community settings. In most cases, 20, the interviews were taken at their homes. In 2 cases they were taken in the offices of the patients. In 8 cases, they were taken in the local schools/sub health posts, during community interactive programmes. Where necessary reinterviews were also taken.

All interviews were recorded and transcribed in Nepali and then translated in English.

The patients and family members were cooperative and enthusiastic for the interviews.

## Interview checklist

- local beliefs & explanatory models of psoriasis  
local knowledge regarding the psoriatic rashes  
local name  
prevalence, incidence  
relation with other severe contagious diseases es., leprosy  
cause/s of the disease  
particular local beliefs in relation to god, evil spirits  
folk, traditional cure
- psychological aspect  
changes in the feelings  
depression, anxiety, frustration  
changes in the attitude  
fear of other people's reactions towards the disease  
change in selfconfidence  
suicidal tendencies  
fear of social stigmatization  
fear of death
- social aspect  
attitude of the friends, family members, colleagues  
social stigmatization  
social isolation  
discrimination at work  
matrimonial difficulties  
difficulty in getting married  
influence in professional choice  
behaviour of the health care takers  
learning to live with the disease  
changes in the social life due to the disease  
behavioural changes
- factors which help to cope with the disease  
folk, traditional cure  
biomedical treatment  
support from family, friends, community members  
religious faith  
counselling  
psychiatric therapy

## *Community interactive programmes*

During the study 4 community interactive programmes were conducted. The first on 3<sup>rd</sup> Nov. 2001 in Taulung- Bhadrakali, Chapali VDC, Kathmandu district, the second on 1<sup>st</sup> Dec. in Phedikhola, Lamatar VDC, Lalitpur district, the third on 22<sup>nd</sup> Dec. in Pipalbote, Nagarkot VDC, Bhaktapur district and the fourth on 12<sup>th</sup> Jan. 2002 in Lamagaon, Talku Dunde Chaur VDC, Kathmandu district. In the selection of the sites for community interactive programmes, the most remote villages with least health care facilities were selected.

The team for the community interactive programmes was formed of the P.I., two doctors ( Dr. Govinda KC & Dr. Beni Amatya) and the R.A.s, along with the supervisors from NHRC.

The following activities were conducted during the community interactive programmes:

- interaction with the local community regarding the psycho-social impact of the skin diseases, in particular psoriasis.
- identification of the psoriatic patients.
- in depth interview of the psoriatic patients.
- free consultation and treatment of skin diseases.
- free medicine distribution.

Altogether 9 psoriatic patients were identified and interviewed.

The community interactive programmes were highly appreciated by the local community members.

## *Group interviews*

Towards the end of the study, two group interviews were taken. The interviews were organized in a local café. The P.I. was the moderator and the R.A.s were observers. In the first interview, 3 patients and 2 family members, all males, participated. In the second interview, 3 female patients participated. In both interviews there was frank exchange of opinion, regarding the psychosocial impact of psoriasis in chronic psoriatic patients.

The interviews were recorded, first transcribed in Nepali and then translated in English.

## RESULTS

The analysis was done using QSR NUDIST programme. An index tree was created by the nodes formed of base datas and the psycho-social variables. The social factors were contagiosity, discrimination, confusion with leprosy, behaviour and attitude of family and community members, difficulties in bathing in public and shaking hands, and problems in going to parties. The psychological factors were sadness, fear and worry. These variables were explored separately in patients, family members in individual interviews and patients and family members in group interviews.

### INDEX TREE

#### (1) BASE DATA

##### (1 1) SEX

(1 1 1)M

(1 1 2)F

##### (1 2) AGE

(1 2 1) <20yrs

(1 2 2) 20-29yrs

(1 2 3) 30-39yrs

(1 2 4) 40-49yrs

(1 2 5) 50-59yrs

(1 2 6) >59yrs

##### (1 3) MARITAL STATUS

(1 3 1)Y

(1 3 2)U

(1 3 3)D

(1 3 4)W

##### (1 4) DISTRICT

(1 4 1) Ktm.

(1 4 2)BHAKTAPUR

(1 4 3)LALITPUR

##### (1 5) RELIGION

(1 5 1)HINDU

(1 5 2)BUDDIST

##### (1 6) PROFESSION

(1 6 1)AGRICULTURE

(1 6 2)HOUSEWIFE

(1 6 3)SHOPKEEPER

(1 6 4)STUDENT

(1 6 5)DRIVER

(1 6 6)LABOURER

(1 6 7)SWEEPER

(1 6 8)WAITER

##### (1 7) EDUCATON

- (1 7 1)NOT LITERATE
- (1 7 2)LITERATE
- (1 7 3)BELOW SLC
- (1 7 4)SLC
- (1 7 5)INTERMEDIATE
- (1 7 6)BACHELOR
- (1 7 7)ABOVE BACHELOR
- (1 8) FAMILY TYPE
  - (1 8 1)NUCLEAR
  - (1 8 2)JOINT
- (1 9)NO. OF FAMILY MEMBERS
  - (1 9 1)0
  - (1 9 2)1
  - (1 9 3)2
  - (1 9 4)3
  - (1 9 5)>3
- (1 10) NO.OF CHILDREN
  - (1 10 1)0
  - (1 10 2)1
  - (1 10 3)2
  - (1 10 4)3
  - (1 10 5) >3
- (1 11)FAMILY INCOME
  - (1 11 1)VERY GOOD
  - (1 11 2)GOOD
  - (1 11 3)NOT GOOD
- (2)CLINICAL FEATURES
  - (2 1)SEVERITY OF THE DISEASE
    - (2 1 1)MILD
    - (2 1 2)MODERATE
    - (2 1 3)SEVERE
  - (2 2)DURATION
    - (2 2 1) <1yr
    - (2 2 2) 1-5yrs
    - (2 2 3) 6-10yrs
    - (2 2 4)11-15yrs
    - (2 2 5)16-20yrs
    - (2 2 6)>20yrs
  - (2 3)INVOLVEMENT OF VISIBLE PARTS
    - (2 3 1)FACE
    - (2 3 2)HANDS
- (3)CAUSES
  - (3 1)BLOOD
    - (3 1 1)DIRTY
    - (3 1 2)FREEZING
  - (3 2)PHYSICAL FACTORS

- (3 2 1) SOAP
- (3 2 2) WATER
- (3 2 3) COLD
- (3 2 4) MUD
- (3 2 5) OIL
- (3 2 6) HEAT
- (3 3) FOOD
  - (3 3 1) MEAT
  - (3 3 2) SALT
  - (3 3 3) BLACK LENTILS
- (3 4) PSYCHOLOGICAL FACTORS
  - (3 4 1) STRESS
  - (3 4 2) MENTAL DISTURBANCES
  - (3 4 3) INTELLIGENCE
  - (3 4 4) AMBITION
- (3 5) SKIN DISEASES
  - (3 5 1) DANDRUFF
  - (3 5 2) SEBORREA
- (3 6) MICROBES
- (3 7) LOCAL BELIEFS
  - (3 7 1) SNAKE
  - (3 7 2) PAST SINS
  - (3 7 3) WITCHES
  - (3 7 4) HEAD IS ON THE GROUND
  - (3 7 5) TAKING OTHER'S LAND ILLEGALLY
- (4) LOCAL NAMES
  - (4 1) SCABIES
  - (4 2) DRY SCABIES
  - (4 3) LEPROSY (MAHAROG)
  - (4 4) 'DADD'
  - (4 5) VITILIGO
  - (4 6) BOILS
- (5) SOCIAL IMPACT
  - (5 1) DAILY ACTIVITIES
    - (5 1 1) BATHING
    - (5 1 2) SHAKING HANDS
    - (5 1 3) WASHING
    - (5 1 4) CLOATHING
    - (5 1 5) WALKING
    - (5 1 6) WORKING
    - (5 1 7) SITTING
    - (5 1 8) COMBING
    - (5 1 9) EATING
  - (5 2) GATHERINGS, PARTIES
  - (5 3) CONTAGIOSITY
  - (5 4) TENDENCY TO TAKE AS LEPROSY

- (5 5) BLOOD DONATION
- (5 6) BEHAVIOUR AND ATTITUDE
  - (5 6 1) FAMILY
    - (5 6 1 1) SPOUSE
    - (5 6 1 2) OTHER MEMBERS
  - (5 6 2) COMMUNITY MEMBERS
    - (5 6 2 1) FRIENDS
    - (5 6 2 2) RELATIVES
    - (5 6 2 3) VILLAGERS
    - (5 6 2 4) HEALTH WORKERS
  - (5 7) RELIGIOUS RITUALS
  - (5 8) ISOLATION FROM THE COMMUNITY
  - (5 9) SECRETIVENESS ABOUT THE DISEASE
- (6) PSYCHOLOGICAL IMPACT
  - (6 1) SADNESS
  - (6 2) WORRY
  - (6 3) FEAR
  - (6 4) FEELING OF BEING HURT
  - (6 5) FRUSTRATION
  - (6 6) SUICIDAL TENDENCY
  - (6 7) ANXIOUSNESS
- (7) TREATMENT
  - (7 1) BIOMEDICINE
  - (7 2) AYURVEDIC MEDICINE
  - (7 3) FOLK REMEDIES
  - (7 4) HOMEOPATHIC MEDICINE
  - (7 5) DIETARY RESTRICTION
  - (7 6) CHINESE TRADITIONAL MEDICINE
  - (7 7) CHANGING RELIGION
  - (7 8) OTHERS
    - (7 8 1) COW'S URINE
    - (7 8 2) WHITE CLAY
    - (7 8 3) COCONUT SHELL WINE

INDIVIDUAL INTERVIEWS

PSYCHOSOCIAL IMPACT IN PATIENTS

SOCIAL FACTORS

### *Contagiosity*

- Most patients and family members are convinced that it is not a contagious disease due to two main reasons:

- doctors have said that it is not contagious.
  - Family members who live together are not affected.
- Patients still have some doubt; some of them use separate combs, do not share cloathes, wash hands after applying medicine and make their children sleep separately.
  - Community members think it is contagious; They think it is leprosy. They objected when one of the patients wanted to donate blood.
  - One of the patient was fired from her job due to this disease.
  - Some healthworkers also think that the disease is contagious.

#### *Discrimination*

- Community members discriminate. Friends didn't wanted to sleep together with one of the patients. To the same pt. community members opposed when he wanted to donate blood.
- Family members discriminate. They do not share or wash cloathes.
- Villagers also discriminate. They avoid the pts.
- One of the pt. was sent away from job due to the disease.

#### *Confusion with leprosy*

- Most patients know that it is not leprosy, although in the beginning they had doubt that it could be leprosy. This is due to the fact that doctors have told them that it is not leprosy and some of them are aware of some signs of leprosy such as dry insensitive patches and falling of the fingers.
- The patients fear that people will take this as leprosy.
- The spouse of one of the pts, treat her badly thinking that it is leprosy.
- Community members tend to believe that it is leprosy. In a village in Dhunche patients with leprosy are separated from others. One of the pt. was told by her client that he would fetch free medicines for this disease evidently referring to it as leprosy. One the pt.s was was told that he musn't donate blood as his body was rotten, most probably referring to the disease as leprosy. Friends and villagers ask if it is leprosy.
- When people call this disease leprosy, the pts. are very hurt.

#### *Behaviour and attitude of family and community members*

- SPOUSE: Most spouses are supportive and understand the problem. In one pt. the husband makes fun of her thinking that the disease is leprosy. In the case of this pt. the husband is also upset that they don't have a son. The husband of one of the pts. was upset when he came to know after their marriage that she had the disease. In one of the pts. the husband seems to neglect her. In her case, the husband has another wife.
- FAMILY MEMBERS: The family members, in particular if the pt. is a daughter in law, do not seem to be supportive. In some cases they have also discriminated. In the case of the male pts. the family members are supportive.



- FRIENDS and community members: Friends are in general supportive. They give consolation and advice for treatment. Community members are suspicious about the disease.
- HEALTHWORKERS: Most health workers behave well. In some pts. there were acts of discrimination.

#### *Difficulty in bathing*

- Patients tend to avoid bathing in public places, due to the fear that others might know about the disease and consequent discrimination. This is more felt by patients without private taps.
- Some patients said that the community members came to know about the disease, after seeing the lesions while they were bathing.
- Patients prefer to bathe at home by fetching water from outside.

#### *Difficulty in shaking hands*

- People tend to avoid shaking hands. In some pts. even friends have avoided shaking hands. In others people avoid shaking hands probably thinking that the disease is contagious.
- Some pts. have developed a special way of shaking hands, just by putting 2 fingers forward.

#### *Problems in going to parties*

- Most patients go to the parties.
- They have tendency of covering the lesions on the visible parts.
- Those with more extensive and very chronic disease tend to avoid parties and gatherings.
- Some never go to parties or gatherings.

### PSYCHOLOGICAL FACTORS

#### *Sadness*

- Patients feel very sad and they relate this to many factors:
  - They think that they are the only one to be affected. This makes them sad.
  - Due to the fact that the disease is chronic with frequent relapses, regardless of the treatment, the patients think that the disease is incurable.
  - According to one pt. even leprosy can be cured, not psoriasis.
  - Target of curiosity and discrimination.
  - The disease is itchy and sometimes painful.
  - Not being able to do certain activities, e.s., bathing in public, swimming, walking.
  - Applying medicine is difficult and time consuming.

#### *Fear*

The patients seem to have some type of hidden fear due to the following reasons:

- Other people's reactions (comments).
- Transmission to children.

- May be related to other serious diseases ,e.s., cancer.
- Spreading of the disease.
- The disease may be leprosy.
- Discrimination from the family members.
- May be the cause of premature death.

### *Worry*

Pts. worry a lot about the disease; following are the reasons of worry:

- The disease will involve the visible parts.
- How to treat the disease.
- Treatment is very expensive.
- The disease never gets better.
- Dependency on others and giving trouble to others.
- It may be leprosy.
- Community members keep on asking about the disease.
- It may lead to some serious disease.

## **PSYCHO-SOCIAL IMPACT IN FAMILY MEMBERS**

### *Social factors*

- Family members do not think that the disease is contagious due to the facts that the other family members are not affected even though they live together, share towels, touch the lesions.
- Most family members do not think that it is leprosy.
- The mother of one of the pts. was discriminated by her friends saying that she has leprosy. To the same patient teachers have told not to come to school.

### *Psychological factors*

- There is general feeling of sadness among family members, in particular the mother.
- They fear that the disease is incurable and can be transmitted to children.
- Worries about other people's reaction and that the disease is not getting better with treatment and if the daughter gets it, there will be difficulty in marriage.

## **GROUP INTERVIEWS**

### **PSYCHO-SOCIAL IMPACT IN PATIENTS AND FAMILY MEMBERS**

#### **MALE GROUP**

- Family members suspect that the disease is contagious. The father of one of the patients initially thought that the disease could be contagious.
- Community members who do not know about the disease think that it is contagious. When there is this kind of thinking, they hesitate touching the patients,e.s., shaking hands.
- Community members think that it is leprosy.

- Patients and family members initially thought that it could be leprosy.
- Patients feel sad up to the extent that one of the patient took poison.
- Patients fear that community members will see the disease, make insulting comments and discriminate.
- Patients also feel that they shouldn't fear as it has no serious consequences.
- Patients worry whether this disease will ever get better When the doctor says that it can not be cured they worry more.
- Patients also worry due to lack of consideration from the doctors.
- After long periods patients tend to get tired of worrying.

#### FEMALE GROUP

- Community members ask if it is contagious.
- Family members said to one of the patients that she should not come with the disease next year as others may be affected.
- Even a doctor thought the disease to be contagious.
- There will be discrimination in old age when one is not able to treat the disease.
- They are sad and the sleep is disturbed.
- Patients fear that the community members will see the lesions and make comments; transmission to children; they will be discriminated when they can not treat and control the disease.
- They worry that the disease can not be controlled and it is spreading.
- They have also accepted the disease and stopped worrying.

#### DISCUSSION

Skin diseases are visible, in particular when the visible parts are involved. This affects the normal appearance of the individuals, which is also known as the handicap of appearance. This significantly affects the psychological and the social life.

Like any skin disease, psoriasis is thought to be contagious. In this study most patients and family members are convinced that psoriasis is not contagious due to the fact that doctors have told them that it's not contagious and family members who live together are not affected. Even then they have some doubt that it may be contagious. In contrast most community members think that it is contagious. Even some health workers think that psoriasis is contagious. This aspect is very important as it is one of the main reason of dicrimination.

Psoriasis is confused with leprosy. Patients and family members initially thought that it could be leprosy. But after the explanation of the doctors and some knowing primary signs of leprosy were convinced that it is not leprosy. But they fear that community members may think that it is leprosy and when someone calls psoriasis as leprosy, they are hurt. In fact most community members think that it is leprosy. Still there is a lot of social stigmatization related to leprosy, resulting in various acts of discrimination.

The fact that community members think psoriasis as leprosy and contagious may be due to the fact community members do not have enough information about psoriasis, while patients and family members are better informed in the process of seeking treatment.

Most of the spouses of the patients understand the problem and are supportive. The family members seem to be supportive in the case of male patients, while less in the case of daughter in laws. Friends are very supportive and give advice for the treatment. Community members are suspicious. From our study the behaviour and attitude of the community members towards the patients does not seem to be appropriate. The family members do not treat well patients who are daughter in laws.

Most patients attend social functions and gatherings. But they cover the lesions while going to these functions. Those patients with extensive disease tend to avoid or do not attend at all these functions. This is mainly due to the fact that patients fear questions, comments and acts which may be insulting to them. For example people tend to avoid shaking hands with patients, most probably due to the fear of transmission. Bathing was a problem in villages where one has to bathe in public taps, due to the fact that community members would see the lesions. Patients tend to hide the lesions.

The disease did not affect significantly the daily activities of the patients much. Most of them could move, and eat normally. In some sleep was disturbed. Some patients complained of pruritus, scaling and difficulty in applying medicines.

Patients and family members felt sad. Those with extensive disease and long duration felt more sad and in one case up to the extent that the patient attempted suicide. The main reasons of sadness were fear and worry generated by certain feelings. The disease being chronic and relapsing patients feared that it may be incurable, and related to some other severe disease. Most patients not knowing others with the same disease, think that they are the only ones to have this disease and this makes them sad. The patients who are mothers fear greatly transmission to their children and difficulty in marriage afterwards, if they are daughters. There is big worry and fear from the patients and family members about the reactions of the community members and the consequent discrimination.

In general the psycho-social impact seem to be more pronounced in patients than the family members.

In the group discussions most of the opinions expressed in the individual interviews were reiterated. Apart from that female patients expressed that cost of treatment was a problem, which would become much worse in old age. There was general expectation that doctors show more consideration towards the patients. Patients also said that they should worry less as the disease has no severe consequences.

In conclusion the patients feared most the social stigmatization due to the disease and this has profound psychological effect making them very sad. There is great fear of the reaction of the community members towards the disease, which usually are discriminatory comments or acts. This in turn affect the harmonious living of the patients and family members in the society. The fact that disease can not be treated completely increases this fear. From the study we have seen that there is significant discrimination from few family members and most community members. There is fear in the patients that the community would reject them and the tendency of isolation from the society. We can say that social stigmatization with consequent psychological impact is the most



Pt. Code no. ....

• clinical datas

surname name/s sex MF

mild (few lesions) moderate (< 10% of the body area) severe(>10%)

onicopathy Y N

arthropathy Y N

erythrodermic type Y N generalized pustular type Y N

involvement of face Y N, scalp Y N, hands Y N, arms Y N, elbows Y N, knees  
Y N, legs Y N, feet Y N

duration of the disease <1yr 1-5 6-10 11-15 16-20 >20

family members affected Y N

difficulties in the following activities: standing Y N use of hands Y N sitting for  
long periods of time Y N sleeping Y N

therapy topical PUVA methotrexate

## Demographic Data:

### 1. Age:

Age / years	Patient	Patient and Family Members
0 - 9	0	0
10 - 19	1	1
20 - 29	8	10
30 - 39	3	8
40 - 49	4	5
50 - 59	3	4
60 - 69	1	1
70 - 79	1	1
Total	21	30

### 2. Sex:

Male	12
Female	18
Total	30

### 3. District:

Kathmandu	16
Lalitpur	7
Bhaktapur	7
Total	30

### 4. Caste:

Brahmin	3
Chettri	5
Newar	16
Tamang	6
Total	30

### 5. Religion:

Hindu	24
Buddhist	6

Total	30
-------	----

#### 6. Marital status:

Married	25
Unmarried	4
Widow	1
Total	30

#### 7. Family type:

Joint family	19
Nuclear family	11
Number of children (if married):	
1	4
2	9
3	3
> 3	9

#### 8. Profession:

Agriculture	5
House wife	5
Shopkeeper	10
Service	2
Doctor	1
Teacher	1
Student	1
Handicraft	1
Driver	1
Laborer	1
Sweeper	1
Waiter	1
Total	30

#### 9. Profession of the spouse:



Agriculture	3
Housewife	9
Shopkeeper	4
Service	3
Doctor	1
Carpenter	1
Peon	1
Driver	1
Laborer	1
Sweeper	1
Total	25

#### 10. Profession of the parents:

Mother:

Housewife	17
Farmer	8
Shopkeeper	4
Service	1
Total	30

Father:

Farmer	17
Service	3
Laborer	1
Carpenter	1
Shopkeeper	5
Others	3
Total	30

#### 11. Education of the parents:

Mother:

Literate	3
Illiterate	26
Below SLC	1
SLC and above	0
Total	30

Father:

Literate	14
Illiterate	8
Below SLC	5
SLC and above	3
Total	30

12. Family income:

Very good	3
Good	13
Not good	14
Total	30

## References

1. Farber EM: Epidemiology: Natural history and genetics. In: Roenigk HH, Maibach HI (eds). Psoriasis, 2<sup>nd</sup> ed. Marcel Dekker, New York, 1989, pp 425-445
2. Shrestha DP: Psoriasis in Nepal: clinical and epidemiological features in a hospital based study. To be presented as poster in the 20<sup>th</sup> World Congress of Dermatology, 1-5 July, 2002, Paris.
3. Richards HL et al: Patients with psoriasis and their compliance with medication. *J Am Acad Dermatol*, 41(4): 581-3 1999
4. Krueger G: The impact of psoriasis on quality of life. Results of a 1998 National Psoriasis Foundation patient-membership survey. *Arch Dermatol*, 137(3): 280-284 2001
5. Fortune DG et al: Quality of life in patients with psoriasis: the contribution of clinical variables and psoriasis-specific stress. *Br J Dermatol*, 137: 755-760 1997
6. Gupta MA, Gupta AK: Depression and suicidal ideation in dermatology patients with acne, alopecia areata, atopic dermatitis and psoriasis. *Br J Dermatol*, 139: 846-850 1998
7. Finley AY & Coles EC: The effect of severe psoriasis on the quality of life of 369 patients. *Br J Dermatol*, 132(2): 236-44 1995
8. Wahl A et al: The burden of psoriasis: a study concerning health-related quality of life among Norwegian adult patients with psoriasis compared with general population norms. *J Am Acad Dermatol*, 43(5 Pt 1): 803-8 2000