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An Exploration of Health, Family and Economic Experiences of Leprosy Patients, Iran

¹Heidarali Abedi, ²Akbar Javadi and ³Sayedali Naji

¹Faculty of Nursing and Midwifery, Khorasgan Isfahan Branch,
Islamic Azad University, Isfahan, Iran

²Department of Medical Emergency, Faculty of Paramedic,
Lorestan University of Medical Sciences, Khoramaubad, Iran

³Faculty of Nursing and Midwifery, Khorasgan (Isfahan) Branch,
Islamic Azad University, Isfahan, Iran

Abstract¹: This study aims to explore the life experiences of Iranian leprosy patients in health, family and economic dimensions. *Mycobacterium leprae* is responsible for leprosy, a type of chronic inflammatory disease that existed from ancient times, still hearing the name of leprosy creates an awful imagination of cutting the organ, blindness and isolation and it has still remained as a serious social problem. The patients are confronted with particular problems physically and mentally. The phenomenological tradition was used to gain knowledge of the leprosy patients lived experiences. Data analysis method was based on Colaizzi's approach. This is a qualitative research using purposeful sampling, interviewing the leprosy patients referring to a contagious diseases department of the Health Network of Nourabad Lorestan City. Data were collected by interviews those were analyzed in Colaizzi's Methods to extract the conceptual codes. Some concepts obtained from the analysis of data in the study such as physical, psychological, social, family, economic experiences, cultural beliefs of society, the context for tendency toward defect and disability and social stigma. These findings suggest that health care professionals should pay attention not only to leprosy patients to reduce their physical and psychological but also to the community and public culture to reduce the leprosy patients suffering from social stigma. The results of the present study can help us in a better understanding of all aspects of patients' lived experiences.

Key words: Leprosy lived experiences, infectious diseases, nursing home care, phenomenology, rural community nursing, family health, Iran

INTRODUCTION

The bacillus of *Mycobacterium leprae* causes Leprosy disease which is a contagious and infectious disease with a terrible image (Eichelmann *et al.*, 2012). WHO (2010) states that leprosy still affects a large populations in developing countries particularly in Africa, Asia and Latin America so there are more than 249 thousand new leprosy patients mainly from Asia and Africa, but the number of cases had reduced from almost 5.4 million in 1985 to less than one million cases in 2002. Also, Nsagha *et al.* (2011) emphasized that six countries could attain to elimination aim of 1 case per 10 thousand during 2004 to 2006. Leprosy transmission being reduced

slowly with a range of incidence annual decline from 2 to 12% using the eradication strategy. The main key factor of this achievement was early diagnosis and treatment. It is predicted that there would be at least one million people with WHO grade 2 in 2020 (Richardus and Habbema, 2007). Also deformity rate of leprosy patients was reduced using early case diagnosis in screening method (Davoodian *et al.*, 2009).

Leprosy is an endemic disease in some countries including China, India and Iran. The incidence rate of leprosy was one in thousand people as the main health problems in 23 countries in 1998, but the prevalence rate of 16 of these 23 countries is over than 3.9 in thousand (WHO, 2003). In India more than 400,000 new cases are

Corresponding Author: Heidarali Abedi, Faculty of Nursing and Midwifery, Khorasgan Isfahan Branch, Islamic Azad University, Isfahan, Iran Tel: +983112717478 Fax: +983115354065

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detected every year. Although, the mortality rate of the disease is not high, the deformity and disability of the leprosy patients are significant community health problems (Rad *et al.*, 2007).

The elimination strategy such as early diagnosis and multiple medicine treatment reduced endemic leprosy transmission in Iran (Golfurushan *et al.*, 2011). The total of 11554 cases were reported in Iran in 2007 with the highest rate in east Azerbaijan but 19% of them (2167 patients) died up to 2007 (Gholchye and Shojaei, 1999). The Ministry of Health and Medical Education of Iran reported that the prevalence rate of leprosy was 0.01 per 10 thousand populations before 2007. But during 2007 total of 32 patients were detected as new cases that were put under treatments (Disease Control Department, 2008). More details were described by Golfurushan *et al.* (2011) who explained that all detected cases were above 15 years old and 56% of them were female, 52% from urban area, 41 % of them had grade 2 disability.

The primary signs of leprosy are skin lesions hypopigmented macules on the cooler areas of the body such as feet, hands and face, with progressive and permanent damaging process to effected tissue. Skin, limbs, eyes and nerves can be affected during the disease progress. The early diagnosis and immediate treatment with multi medicine controls the disease progress and eliminate the public health contamination (Nsagha *et al.*, 2011). One of the major problem of leprosy case findings is hiding the sign of disease by patients due to leprosy stigma. In other word, leprosy patients are suffered from not only physical pain but also psychological and social health problems. They are not accepted by social that affect their right to live as a normal individual can do (Rafferty, 2005).

Leprosy is a type of chronic inflammatory disease that existed from ancient times and hearing the name of Leprosy creates an awful imagination of cutting the organ, blindness and isolation and it has still remained as a serious social problem. The leprosy can damage the body structure and deforms the effected body parts and lead to disabilities. The results of such form of body present an awful picture of patients that is main reason for social stigma. The leprosy patient with damaging body is not able to work and they lose their job and their economic independence. Moreover, they may lose their self esteem and quality of their life as a result of leprosy stigma (Bainson and Van Den Borne, 1998).

The patients are confronted with particular physical and mental problems. Although the disease is being eradicated, lived experiences of such patients have not been explained and recorded as part of leprosy history. This study amid to explore the leprosy lived experiences in one part of Iran.

MATERIALS AND METHODS

The method of this study was qualitative method using phenomenology approach that is a way of describing lived experiences as a phenomenon that has not been clearly described and explained (Yousefi *et al.*, 2009). The study population comprised all patient had suffered from leprosy in Lorstan province of Iran. Inclusion criteria were those who experienced living with leprosy disease and having an interest to participate in the study. Sample were selected using purposeful sampling method (Abedi, 2010) and the sample size increased based on the need for information up to data saturation (Burns and Grove, 2010), finally a total of 10 participants were chosen.

Participants' consent was obtained through giving them full explanation about the research method, aims, researchers' and participants' role in the research then, data were collected by in-depth interviews. The ethical consideration was observed by asking participants to fill out the consent form before recording the interviews. Each interview was lasted for 40 to 50 min. Then, the recorded data verbatim were written word by word and rechecked. Data analysis was based on Colaizzi's Seven Steps of Phenomenological Analysis (Holloway and Wheeler, 2010). First, all manuscripts were read many times to get familiar with the participants idea and feeling. Then, the important phrases were extracted as the basic codes from each related important phrase. In the next step every interrelated basic codes were integrated to one category as sub themes and finally integrated those the themes.

RESULTS

First step: Tape recorded interviews transferred to handwriting and were read many times by the researchers to get full familiarity with participants idea.

For example participant 4 said that:

My parents were both suffering from leprosy, I also got the disease, we generally "were a few families who had to live far from the village". Lack of health facilities, poverty as well as neglecting me by my parents led my disease symptoms evident and during a few years my face deformed to current shape (destroyed nose cartilage, flat-swelling face, losing eyebrows).

Next step, the researchers highlighted the important related phrases as you see the below paragraph.

My parents were both suffering from leprosy, I also got the disease and we generally "were a few families who had to live far from the village Lack of health facilities, poverty as well as neglecting me by my parents led my

disease symptoms evident and during a few years my face deformed to current shape (destroyed nose cartilage, flat-swelling face, losing eyebrows).

The primary codes were obtained from important related phrases that were highlighted in the manuscripts text. These above highlighted sentences were into account as basic codes and some basic codes were formulated such as:

- Get the leprosy from their parents
- Far from the village or society isolation
- Lack of health facilities
- Poverty
- Neglecting

Disease symptoms (physical deformation): Another example, participant 6 said that, after the death of my parents, the government had asked the people who lived far from that area, went to Tabriz Leprosy Village and stayed there until five years ago. During this time I never think about marriage and even I didn't want to think of this issue as well, because I knew no one accept me as a husband.

These basic codes were formulated from the above highlighted sentences:

- Leprosy village
- Never think about marriage
- No one accept me

Participant 9: Now, I have no sense of smell, no job and income, just people help me for sake of God. I wish that

God kills me as soon as possible to get me of from this painful life. For many years I have been alone, no one sit next to me and talk to me for even a few moments. Poverty, far from health services, the compulsory relocated, begging, to remain unmarried, thoughts of death, remain sideline and isolated, to burden the stigma tag of disease and being transmitted to the community, living without parental care, deformation of my body parts (losing eyebrows and flat-puff-stained face, not accepted by the community, wish to die.

The following basic codes were extracted from the above highlighted sentences:

- No sense of smell
- No income
- Painful life
- To be alone
- Poverty
- Compulsory relocation begging
- Unmarried
- Thoughts of death
- Remain isolated
- Stigma

Deformation of the body parts (losing eyebrows and flat-puff-stained face, not accepted by the community, wishing to die.

All of manuscripts were analyzed using the Colaizzi's analysis approach similar to the above examples. Continuing the above method, resulted in extracting 81 basic codes that are shown on Table 1.

Table 1: The list of the basic codes extracted from participants' interviews

Primary codes	Primary codes	Primary codes
Get the leprosy from their parents	Lesions	Understanding family
Far from the village or society isolation	secretion from the lesion of inflation an	divorce
Lack of health facilities	Analgesia affected area	remarriage
Poverty	Members feel isolated from	sick husband
Neglecting	Member with the smell of putrefaction	away from the patient's family role
Disease symptoms (physical deformation)	Skin spots	losing family
Leprosy Village	Swelling of the skin	values and character in children
Never think about marriage	Scarring risk area	drug addiction
No one accept me	Frequent recurrence of ulcer	children irreverent
No sense of smell,	Cramps and bleeding from the nose	Understanding family
No income,	Deformed nose	divorce from husband
Painful life.	Loss of sense of smell	wife separation
To be alone,	Loss of brow	study failure of children
Poverty,	Loss of leg	to blame excuses wife
Compulsory relocation	Breathing problems	expulsion from the family
Begging,	Cataract	household distress
Unmarried,	Blindness	prohibited from leaving home
Thoughts of death,	be bloated	stay single family
Remain isolated,	Slow movements	being hated from society
Stigma	behaviour problems	lack of social support
Deformation of the body parts	Crying memories	upset
Losing eyebrows	tears when remind	to escape
Flat - puff - stained face	Avoid witness alone	the shame of social ridicule
Not accepted by the community	Fatigue	withdraw from social activities
Wishing to die	Decreased ability	Feeling of being guilty
Feeling empty	Lesions	tension of see the world
Feeling of homesickness	secretion from the lesion of inflation an	Hopelessness and despair to being alive

Table 2: The list of sub themes and themes extracted from the basic codes of participants' interviews by integrating the basic codes to 10 categories and 3 themes

Sub themes	Themes
Economic experiences related to patient experiences related to family economic	Economic experiences
Family experiences related to the patients	Family experiences
Family experiences related to the family	Health Experiences
Physical experiences	
Psychological experiences	
Side effects	
Feeling effects	
Emotional factors	
Society reactions	

After listing basic codes, researchers try to find out the similarity of basic codes concept and group them based on similar meaning. The interrelated basic codes were integrated to one category, that comprised of 10 sub themes and finally integrated those to 3 themes as they are demonstrated in Table 2.

DISCUSSION

All leprosy patients' life dimensions negatively affected in most situations. The health, family and economic situations of them are highly discriminated and leprosy patients' experiences could be more serious. The recently published review highlighted that there are many health problems for patients living with leprosy (Lasry-Levy *et al.*, 2011). In this study showed that the structure of patients' life experiences are that it is explained as a core concept including: health, family and economic experiences.

Health experiences: The results show that there are some different aspects of leprosy patients life experiences. They encounter with numerous inevitable leprosy complications which reflect reality of their life and make them vulnerable groups. A published study emphasized the importance of an individual's overall view of life rather than specific coping strategies for health and wellbeing (Rohani *et al.*, 2011). Darani *et al.* (2010) had found in their study similar to the study findings that, these patients believed that they were never asked about their problems needs and demands and their remarks have not been considered in health care planning. The theme "health experiences" is one of the basic concepts in this present study that showed leprosy patients' life affected in different dimension such as Psychological experiences, Side effects, Feeling effects, Emotional factors and Society reaction. When a person got leprosy encounters one psychological experiences as the previous study showed the psychological problems of leprosy patients (Lasry-Levy *et al.*, 2011).

Family experiences: One participant said that people should know that we are also human beings and we have the right to live, we have our case like a harvest that is on fire and others that wood is (it means that we ourselves have plenty miserable problems so that we have been disabled but not only we suffer from society isolation but also from disability to do our roles in the family). This finding is supported by Zodpey *et al.* (2000) findings as they found that such isolation from domestic roles develops among women a self-image of being a less valued member of the family. Rafferty (2005) emphasized that people with leprosy may lose their employment because of their disease, the disabilities associated with it and negative attitudes of employers. When this happens, they lose the means of supporting their families and often the respect of their communities, with loss of self-esteem. Such patients had helplessness feeling as one participant said that "never my family understand me, the never support me, they left me alone with a huge problems". This finding is similar to Salarvand, Abedi *et al.* (2008) as they found in their study that most families did not understand the needs of their family members during the crises.

Economic experiences: Poverty and low socioeconomic status of leprosy patient were explained by participant similar to study results of the leprosy patients in Kerr-Pontes *et al.* (2006) and they suffered from social problems and more social stigma, also they experienced isolation and rejection of the society as Kushwah *et al.* (1981) explained similar situation for leprosy patients. Abedi *et al.* (2012) studied the economic such patients and said that, going frequently to the hospital and its cost, clinic costs, frequent hospitalization, high therapy costs such as: medicine costs and remedial pursuits caused the increase of life costs for those patients that some of them forced to sell their houses and cars and family income lead to the creation of the economical problems for the patients and their families. Also in this study economical pressures caused the poverty, excruciating life, and the feeling of being a burden. In addition to the above costs, the patients that lost their job hadn't any incomes. One participant said that "no one accepts me as worker and I had never job, no income, I am disappoint".

CONCLUSION

The results of the present study indicate a dimensional picture and deep description of life experiences of leprosy patient who suffering from

different problems. In all leprosy patients, the description of daily living story is full of miserable experiences and negative feeling and social stigma. The health, family and economic situations negatively affected by leprosy disease. They need a comprehensive health care program. To look at such story may help health care provider and social policy maker to better understanding of all aspects of such patients' lived experiences. Sarrafzadegan *et al.* (2012) argued that a comprehensive health promotion intervention programs must be planned as a comprehensive community based program. All of the health policy makers and health sectors have to cooperate to implement these kinds of interventions. Community health nursing is one the main health promotion program. Therefore, to achieve success in implementing a community care for leprosy patients, nurses must work with other parts. The results of the present study indicate a clear picture and deep recognition of life experiences and process of disease in this group of patients and it can help us in a better understanding of all aspects of patients' lived experiences.

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