

# A PHENOMENOLOGICAL STUDY ON LEPROSY CLIENTS' EXPERIENCE IN HAVING LEPROSY TREATMENT AT JENGGAWAH PUBLIC HEALTH CENTER AREA AT JEMBER, EAST JAVA, INDONESIA

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## ABSTRACT

A part of our population that is mainly at risk in the community is the leprosy clients. They faced problems in physical, psychological, social, economical, and spiritual aspects. Such problems are needed to be managed by providing treatment that prevents disturbance in body function as well as empowers leprosy clients in the community to be efficient enough to fulfill the demands of daily life. The purpose of this study is aimed to gain the value and meaning of leprosy adult clients' experience in having leprosy treatment in the community. The study was done by qualitative approach in descriptive phenomenology design. The data collection method was done by in depth interviewing and taking field notes. The participants were leprosy adult clients who are under treatment and MDT medication at Jenggawah Public Health Center Area in Jember. The data was treated into interview transcripts and then was analyzed by Collaizi's technique. The study results are themes which are namely negative response when diagnosed to leprosy, positive response when diagnosed to leprosy, body image, disease description, client compliance to MDT, ability in fulfilling the basic needs, ability to have self care, types of services or assistance, implementing family health task, expectation to self, expectation to family, expectation to society, and expectation to Public Health Center. The results of this study showed that adult clients' experience in having leprosy treatment were unique and have a large range of variation and therefore it needed support from all parties to make leprosy clients healthy, independent and productive in their life. These results are expected to be a foundation for prevention and promotion program as well as leprosy clients' health protection in having leprosy treatment by integrating community nursing intervention model and involving the relevant institution.

*Keywords: leprosy clients, leprosy treatment, community*

## BACKGROUND

Leprosy represents a disease that owns high burden in society or is referred to as disease with triple burden (Azwar, 2000). According to data WHO year 2005, Indonesia occupies third sequence in world. Lepers in Sub-Province Jember in the year 2008 were noted to be 463 patients and year 2007, 538 patients (Sub-district Health Department Jember, 2009; MDI, 2009). The data from Community Health Center of Jenggawah (year leprosy data 2001–2008), got by the amount of lepers which enlists counted 9 people. Type PB leper counted 2 cases and MB leper counted 7 cases. Prevalence Rate leprosy in Community Health Center of Jenggawah is 265 per 10,000 resident. New case of leprosy which is still found in community resulted by still lower awareness of leprosy clients and society, in handling the problem of leprosy (Suryanda, 2007). Leprosy handling in community requires same activity from health officer, society and client in consequence of psychosocial and physical problems generated by leprosy disease in community (Zulkifli, 2002).

The problems of physical leprosy client in Jenggawah society like situation of leprosy hurt or injury which progressively deteriorate and handicap; these emerges to result a society that has negative opinion for leprosy clients. This matter affects the social and psychological life of leprosy clients in Jenggawah society. Problems of physical leprosy clients emerge due to lack of information, mistake of information, wrong ascription, magic, and fear to leprosy disease (Gokhale, 1996). This affects the problem of the leprosy client's psychosocial condition by how people view this disease. The people's negative attitudes towards the clients affects the treatment. The society is prone to label appearance, attach stigma and socially discriminate the leprosy client (Wokaunn, 2006). The Jenggawah society still assumes the condition of leprosy as a hideous disease and the patient often goes without a treatment. The social discrimination results in deterioration of the client's condition and often results in extreme incidents of handicap. So new leprosy cases are continuously found in the society (Suryanda, 2007).

Such problems require special measures from health officers. Community nurse as one of the health officer in society is better accomplished to

handle leprosy clients through approach of upbringing treatment (Nies & McEwen, 1997). Upbringing treatment of the community of application can be a special program to handle problems of leprosy. One of the way of community nurse which can do to guarantee to continue an health service or program in applying promotion program, protection, and prevention is with forming partner to handle risk at population in community (Helvie, 1997).

Problems of leprosy in society need good management related to its treatment to prevent function trouble and is powered of leprosy client in optimal life in a condition illness to fulfill requirement of everyday life. Pursuant to this phenomenon require to be conducted by research qualitative with descriptive phenomenology design to identify meaning and meaning experience of leprosy client experiences treatment in society. Researcher formulate research question that is: What meaning and meaning experience of adult client experience treatment of leprosy in region work Community Health Center of Jenggawah sub-province Jember. This Research aim to obtain and get meaning picture and meaning experience of adult client experience treatment of leprosy in region work Community Health Center of Jenggawah sub-province Jember, East Java, Indonesia.

## METHOD

This research used research method qualitative through approach of descriptive phenomenology design. This research dig leprosy client meaning and meaning experience in treatment of leprosy. Treatment of client leprosy represents a very life experience of natural complexes by leprosy client. The life experience relate to problems of everyday life of good before diagnosed by leprosy and also after diagnosed by leprosy and experience treatment of leprosy. Problems of client leprosy experiencing treatment relate to requirement of physical, psychological, social, and medication and also handicap. Data taken away from by 10 leprosy client participant experiencing treatment in region work Community Health Center of Jenggawah sub-province Jember with leprosy client inclusion criterion and experience program medication of Multi Drugs Therapy (MDT), not yet experienced of function trouble and experience of permanent handicap

able to bother interaction during intake of information, remain by their self or with family, comprehending its disease process and can communicate the experience with Indonesian, and ready to participate in research. Method intake of sample is purposeful. Intake of data executed in March up to May month 2010.

This research use guidance of autonomous research ethics, malfeasance and beneficence, and justice. Data collecting through guidance of interview, field note (stain field), and MP4. Step Process analyze data at this research use Colaizzi steps (1978; in Streubert & Carpenter, 2003). Authenticity of this data research is relied on credibility, transferability, dependability, and confirm ability.

## RESULT

There were ten adult clients who participated in this research who received treatment for leprosy in region work Community Health Center of Jenggawah sub-province Jember. There were eight male and two female participants. Participant's age varied between twenty five years to seventy years. Level of education of participant varied starting from elementary level up to high school, and their occupations are merchants, farmers, housewives, and labourers for carpenter or builders. Participants come from ethnic Java are five client and ethnic Madura are five client.

Duration of experience in treatment of leprosy start from three months up to eleven months. During experience in treatment in society and family, leprosy client in a period of medication of leprosy in Community Health Center of Jenggawah by getting MDT package. Member family participating in taking care of leprosy client is husband, wife, and his child, both are old fellow from leprosy client. Participant altogether remain with its family of goodness in the form of extended family (big family/generation) and also nuclear family. The history of family member suffering leprosy one participant, and natural degree of handicap 0 is one participant, defect 1 is one participant, and handicap 2 are eight participant. All participant in research suffer MB type leprosy.

Identified by thirteen theme experience of adult client experienced treatment of leprosy. Theme (1) diagnosed by negative response of leprosy depicted in sub theme denial, drive a bargaining, and depression.

Theme (2) diagnosed by positive response of leprosy depicted in sub theme accept reality. Theme (3) their self picture depicted in sub theme awareness of theme and their self. Theme (4) disease picture depicted in sub theme of its understanding of leprosy disease. Theme (5) compliance drink MDT depicted in obedient sub theme, is not obedient, and sigh to medication side effects. Theme (6) service type or help depicted in magical sub theme or culture, traditional, health service center, and delay of health officer handling. Theme (7) ability to fulfill elementary requirement depicted in work sub theme, eat, sleep rest, and environment. Theme (8) ability to conduct treatment by their self sub theme take a bath and dress. Theme (9) doing treatment according to duty health of family depicted in sub theme recognize problem, taking decision, take care of, looking after environment, and exploit health service. Theme (10) expectation to own self depicted in sub theme bevy of activity of leprosy. Theme (11) expectation to family depicted in wanted family support sub theme and support type. Theme (12) expectation to society depicted in social relation sub theme. Theme (13) expectation to Community Health Center depicted in health promotion sub theme and health service.

## DISCUSION

### *Response Diagnosed by Leprosy*

Client leprosy at early stage diagnosed of response negatively (like refusing, drive a bargain, and depression), but none of the client, time of response positively by accepting the reality. Leprosy client in creating strategy in face of loss and sorrow in this research through four step, that is denial (shock, unconvinced, refusing, and shame), drive a bargain, depression, and acceptance. (Kobler Ross, 1969; in DeLaune & Ladner, 2002). Individual experiencing sorrow will be divided to become same phase that is deduction, angry, drive a bargain, depression, and acceptance. Feeling cross with this research do not emerge but at client with Madura ethnic characteristic show angry attitude with self defeating behavior of him like deciding radius his arms by own self. This matter as according to Madura ethnic characteristic which is temperament and easy to fulminate. Angry response did not emerge in this research also because some of

client came from Java ethnic, measuring up to gentle and always accept situation. Client in this research is also identified to get support from its family so that angry respond which felt by client do not be said and do not be peeped out by effect of the support. Groot de (2002) telling there is consistent relation between low social support with degradation of health of physical and bounce individual.

Big Psychosocial support at bosom cancer patient will assist repair of health and his relation with quality of life of bosom cancer patient. Gift of the support will be able to give positive response at individual. Positive leprosy respond client through acceptance to be diagnosed by leprosy. Acceptance of client in this research is based on allow to follow medication program of MDT leprosy package during six-month and or one year. Decision making in acceptance of medication and disease in this research is very determined. The existence of natural pandemic information by client from health officer and also client's perception in handling the situation of disease and own self will affects decision making. As per Engel (1969; in DeLaune & Ladner, 2002) sorrow to experience of by someone at resolution and restitution phase will mark with client accept reality of loss to round into and awareness of own self.

### **Perception Own Self and Disease**

Clients perceptions of disease and self identification in awareness of disease picture. Client in giving own self picture can comprehend situation of own self will unfavourable. This matter relate to situation of awareness of own self concept and own self health by related client of its condition in this time so that will give the understanding of unfavourable good own self picture. Own self picture can give form incarnation of own self physically so that individual will depict and feel about themselves as a whole both for consciousness become unity in own self picture (Stuart, 2009). Wal and Blasshil (2010) doing research about the role of body image dissatisfaction and depression on HAART adherence in HIV positive men: tests of mediation models. Result of research indicate that there is relation between unsatisfied of own self picture and HAART which do not bow to people with diagnosed result of HIV/AIDS.

Some clients in this research are also with well comprehended leprosy perception. Clients giving pathological picture relate to situation as described by leprosy the condition of disease which is suffering by client in this time. Client in giving the picture can be good pursuant as natural as it. Kosasih (1997) identifying qualitative result of directional group discussion (group focus discussion) known as the most elite figure have good knowledge and positive attitude to leprosy disease in sub-province Kuningan, province West Java in the year 1996.

Pithcard (1986) along with its own information from past and through learning process, consider the information system organization through thinking and reasoning, perception making, decision making and form cognate function as response to its environment which change. In this research the leprosy client generally get pathological information of leprosy from Community Health Center (CHC). CHC in giving the pathological information to leprosy client will have an effect on the pandemic client perception of him.

### **Management Medication of MDT (Multi Drugs Therapy)**

Client leprosy in experiencing medication management in this research relate to compliance of client take MDT. Compliance of client take medicine in this research relate to the existence of uncomfot and or natural sigh by client during following medication management. Leprosy client obeying order to take MDT in this research is also supported by existence of positive impact from medication of leprosy. According to Hardyanto in Saranani (2005; in Hutabarat, 2008) medication of leprosy, is mainly regularity and adequacy of intake will lessen the condition of which is infection forms, disobedience and irregularity in taking medicine at leprosy client will cause very ugly condition of drugs resistant leprosy at leprosy client.

Harjo (2002) showing result of research of irregularly medicated leprosy client equal to 32.31% and regular medicated equal to 67.69% from 208 leprosy responder in Majalengka. This Matter relate to knowledge, client attitude, role of health officer, and availability of medicine in CHC to irregularity of client with medicated leprosy. Masduki (1993; in Hutabarat, 2008) showing result of research mount

compliance of leprosy client which medicated equal to 83.5% and 16.56% is not obedient medicated at leprosy client in sub-province Kuningan, West Java. This Matter relate to education factor, work, gender, knowledge, handicap and perception effect of leprosy disease to compliance medication.

Client with noncompliance to medication of leprosy shown to pass behavior impinge order gift of drug. Leprosy client in impinging giving medication to leprosy in this research relate to less trust in medication. Oesman (1993) factor having big role in regular medication is trust of patient (85.76%) and disparity of leper husk (86.42%) in sub-province Tangerang 1989 – 1991. Sunanti and Rachmalia (1991; in Hutabarat, 2008) pursuant to result of research qualitative in sub-province Bangkalan shows that leprosy client perforce to medication to health officer because ashamed of the disease and client family believe that leprosy disease resulted from by the existence of philtra, disease because magic and anathema, so that client will take medication by health officer have in a very hard state. This matter will affect at therapeutic management medication of leprosy which is not effective.

Some of natural leprosy client, uncomfortable to medication side effects in this research experience of noncompliance in medication. This matter differ from research of Hutabarat (2008) expressing there is no side effects in relation to medication with compliance to take medicine at leper (58.1%) in Sub-Province Asahan in the year 2007. This research identify the existence of uncomfortable side effects related to natural symptom and sign by client effect of medication, feeling of client after taking medicine, and effort done by client to lessen side effects that happened so that this matter will have an effect on to compliance of client in medication. Perception to felt by side effects at leprosy client getting MDT relate to felt symptom and sign and also how leprosy client mean and interpret natural side effects of symptom and sign. Hutabarat (2008) expressing there is relation reaction of leprosy with compliance take medicine leprosy at leper (51.2%) in Sub-Province Asahan year 2007. Boggild (2004a) gift of MDT to the each drug combination, sometime generate unwanted side effects. Side effects to the each usage medication differ each other in each leprosy client and vary with the character individually.

Some leprosy client in this research interpret the side effects mentioned as reaction of normal because they take medicine and some client worry and have fear because of opinion of its condition progressively deteriorate. This matter need an information which either from health officer to anticipate undesirable things and leprosy client so that can take an effort to overcome the side effects. Result of research of Harjo (2002) show that is statistically obtained by relation having a meaning of role of health officer (OR: 2,91, 95% CI: 1,60-5,31) with irregularly medicated leper [in] Sub-Province Majalengka year 1998–2000. Some leprosy clients have experience of allergy to one of the drug from MDT combination. Allergic sign which generally will emerge is happened to squeeze at husk and itch or black spot at husk. Oesman (1993) from calculation of risk attributable exposed obtained by result of disparity of husk 86.42% to regularity medicated leper in Sub-Province Tangerang 1989–1991. If there are these cases, client asked to discontinuation of consumption of MDT and referred to CHC or nearest.

#### ***Daily Living Activity (ADL) Before Diagnosed by Leprosy***

ADLs of client before suffering leprosy in this research is found by two theme that is ability of client fulfill elementary requirement and ability of client do treatment by them self. Fulfilled elementary requirement will determine individual health level and its position in spanning health and sick. Individual ability in fulfilling elementary requirement in this research for example: work, eat, sleep and rest, and also environment. There is some client which do not work and or work even also with fear for not doing it after society know that client suffered from leprosy. There is various influence variable, like work (P=0.037), labour (P<0.05) and low production of P=0.029 ( P<0.05) to regular medication effort which done by leper in Sub-Province Gresik (Fajar, 2001). Stanhope and Lancaster (2000) shows leprosy client represents risk at population with approach of risk in economic factors. This matter of economic factor relate to occurrence of leprosy which [is] generally suffered by client from social economic is less.

Disparity of physical and handicap that happened

to client in this research is initially resulted from by accident of job activity. This matter because of client is less protecting of own self in work. There are a number of defects and 50 (52.1%), and there is a significant relationship ( $p < 0.05$ ) between: Type of leprosy with a disability reaction with defect, taking medication with a defect, jobs with defective, been ill with a disability and there was no significant relationship between the welfare and education with a disability (Gunadi, 2000). Some effort done by leprosy client in this research among others use footgear to protect its feet from hurt. Usage of special shoe of leprosy client indicate that use of special sewed cloth shoe is very cheap and protecting, cost effective, and preferred than orthopaedic shoes (Seboka 1998; in Britton, 2004).

Leprosy client who does not work hence by inclusion of earnings of family will decrease so that economic requirement of family become to decrease. This matter differ from result of research done by Gunadi (2000) expressing that there do not have any relation between prosperity level and education with handicap. Hitchcock, Schubert, and Thomas (1999) shows condition of and handicap limitation was peeped out physically at leprosy client in community was also made worsen by less nutrition factor of adequate. Pagolori (2003) identifying that low nutrition status have risk 3.35 times more to happened reaction of after medication of MDT than good nutrition at leper in Sub-Province Gowa year 2002.

Accomplishment of requirement with enough nutrition generally relate to social situation of leprosy client economics. Suhariyanto (2005) done research of retrospect in to leper take care of road Health of Husk and Genital RSUD, Subandi Jember year 2000–2004 showing 55.55% patient at social group of low economics with work of pedicab worker and labour occupy highest rank that is equal to 230 patients. Boggild (2004) leprosy disease progressivity can be prevented with make-up of immuned status of leprosy client. Immunity at leper required to take care of its health status and lessen disease progressivity. Iskandar (1998) identifying relation between bacteriologic inspection of serology at leper got by MLPA test seropositivity as level mount from tuberculoid form toward lepromatous form (and  $p < 0.001$ ) improvement of Ig M antibody titer from lepromatous to tuberculoid

form ( $p < 0.001$ ). Titer MLPA mount linearly along with make-up of IB ( $r = 0.65$ ;  $p < 0.001$ ). Make-Up of IB is also followed with make-up of Ig M titer linearly ( $r = 0.78$ ;  $p < 0.001$ ). MLPA test and ELISA for the inspection of IgM at PB group 73.8% and MB 92.7%.

Indian research study shows 63% cases of infection with leprosy transmitted between house to house and generally relate to the availability of less enough nutrition (Kumar 1999). Accomplishment of requirement of nutrition fulfilled will be able to be exploited in an optimal fashion by body if supported with accomplishment of requirement of taking rest and sleep. This research identify the duration of client sleep in one day vary between two to five hour, while to take a rest between one until two hour one day used up client work. This matter will affect at condition of lethargy (fatigue) at client. Pagolori (2003) identifying that fatigue become risk factor to the happening of reaction of after medication of MDT at leper in sub-province Gowa year 2002. Environment around leprosy client determine the occurrence of leprosy. Ruswan (1997) identifying 1 among contacted 3.6 house suffer leprosy. This matter relate to some factor that is sanitation hygiene, old contact, friendliness ( $p < 0.05$ ), and friendliness variable having strongest relation (POR=6.87).

Characteristic family in this research generally is big family which remain in one house so that have contact among family members and density in house environment. This matter will affect at occurrence of leprosy. Matasik (2002) done research about risk contact leper, and RFC RFT to occurrence of leprosy in region work CHC Bantimuring sub-province Maros. Result of analysis conclude that risk of suffering leprosy at one with history of contact compared to one with no history of contact house. Risk of suffering leprosy at one with history of contact compared to higher neighbour with no history of contact neighbour. There is no difference of risk of suffering leprosy at solid family member and which is not solid at house contact with leper.

Hygiene pattern of clients own self before pain in this research depict client hygiene personal characteristic related to hygiene of husk. This matter because of leprosy represent contagion owning

individuality of its existence of disparity at client husk which generally relate to hygiene personal. Ma'Rufi, Keman and Notobroto (2005) identifying individual hygiene like bath frequency, wearing soap or not, hair bath, frequency of use of clean towel and clothes, sharing of towel and clothes, and hygiene of pallet sleep to scabies disease prevalence through study at Moesloem students in Islamic Boarding Schools sub-province Lamongan in the year 2003–2004. Result of research show most Moesloem students (213 people) having bad individual hygiene with scabies disease prevalence 73.70%, while Moesloem students with individual hygiene of goodness (121 people) having scabies disease prevalence 48.00%. This matter can be concluded by role of individual hygiene in infection of scabies disease (Chi Square,  $p < 0.01$ ). Badri (2004) healthy and clean life behavior especially civil hygiene in Islamic Boarding Schools Lamongan in general less is getting of attention from Moesloem Students. The mentioned matter can cause incidence of scabies. Factor influencing infection of this disease is low economic social, bad civil hygiene, ugly environmental sanitation, behavior which do not support health, and solid dwelling. Conservancy of hygiene of Moesloem Students own self main action to look after the health and hygiene of own self for the prosperity of physical and of psychological (Badri, 2004).

### ***Effort Overcome the Problem of Leprosy***

Leprosy client in search of help to overcome its problem in this research was identified to pass traditional service, magic service or culture, and modern health service. This traditional medication service depict drugs used by client for self support. Sunanti and Rachmalia (1998; in Hutabarat, 2008) find in Bangkalan, Madura society classify disease become two fraction, caused by disease is smooth matters (disease and magic) which because of condition of bad body. Participant looks scabby into the condition of pain, scabies and cough is not such a condition of pain. This matter because of the condition can be healed by formal medication and or can cure by own self traditionally.

Snyder and Lindquist (2002) mention complementary therapy represent one of the area of healing in all health system, modality, and also

some factor like culture and social hereditary. Foster and Anderson (1999) trust of client will influence to seeking of health service and health behavior of client in striving. Leprosy client in this research use cultural or magical medication is also influenced by the duration of illness and use of the cultural or magical medication service. Nicholls (2002) identifying postponement of progress of leprosy in knowledge context and local attitude in Paraguay, who qualitatively got that traditional medication, for example seeking of soothsayer or smell magical which experienced by leprosy client generally less effective in healing of leprosy disease and oppose against health intervention so that add hard condition of leprosy client.

Suryanda (2007) identifying societies perception to leprosy through case study in district of Cambai Prabumulih South Sumatra, that the disease is deed sin by leprosy client and is irremediable. This matter will result leprosy client medication to traditional alternative service for example cultural or magical service which relied on local society culture and trust. Health service have to comprehend healthy concept of ill role and pain pursuant to condition of culture and society by client (Ember and Ember 2004). Health officer have to be sensitive to local culture by conducting approach carefully so that given intervention can be accepted by society. Community nurse as part of health officer in society have to learn to do cross cultural health service to give good service. Community nurse can do transcultural nursing to give service treatment of sensitive community to local culture (Leininger; 1978; in Omeri & Mcfarlan, 2008). Dharamshaktu (1996) identifying the effort controlling of leprosy in India, that adequate health service represent an requirement which is needed by leprosy at risk populations. Out of reach health service by leper generally happened because cloistered residence so that will add risk of the problem in the leprosy population.

### ***Treatment of Family***

Client and family assume leprosy disease, according to its life field as resulted by disease is magical matter so that look for help to medication of alternative by going to soothsayer, bright people, and ustadz. Result of research of Racmalia (1998) about development model of leprosy treatment in endemic

area with social approach of culture in Countryside Banyuwangi, sub-province Bangkalan Province East Java qualitatively identified that in general leper know catching and dangers of leprosy, in consequence if have been adjudged as moment leper check, hence he tend to isolate own self especially if there is disparity of body.

Family client in this research also less aware about of leprosy cause, symptom and sign which is natural client. Some client in this research express leprosy as disease which is not catching and also its cause because occult matter and philtra by others pursuant to from sign characteristic and natural symptom and feeling of. Result of research of Rachmalia (1998) about development model leprosy disease treatment in endemic area with social approach of culture in Countryside Banyuwangi, sub-province Bangkalan Province East Java qualitatively identified by some from leper believe that leprosy as generation disease or resulted from magic. Because its medication is prolong, they tend to look for medication of alternative to soothsayer which according to them earn quicker heal in leprosy. This matter results in problem in decision making by family.

Decision making in this research depict natural impact by client. The impact represents effect generated by leprosy. Leprosy impact in this research can be grouped to become some sub theme that is stigma and labeling and also leprosy client discrimination in community. White (2008) done qualitative research about clarification of very complex leprosy disease in Brazil. This Research identify that labeling at leprosy client given caused by an condition of which physically emerge effect of leprosy disease. Wokaunn (2006) studying regarding leprosy picture and stigma in Croatia identify that participant assume physical invalidism at own self result to feel small and lower own self as effect made by stigma and labeling is society around leprosy client. This matter will generate to feel of no use, fear, shame, and lower client's self psychology.

Jacob (2008) studying about approach to overcome stigma in India, results indicate that discrimination represent a treatment of individual or classify one with prejudice or partiality. Client family to take care of leprosy disease in this research

relate to harsh or dry husk and hurt, food, bath, and support during taking medicine. This matter was done to prevent handicap at leprosy client. Junaid (2002) done research about leprosy handicap and its determinant in Puskesmas Batimurung sub-province Maros region, results indicate that there is an relation between regularity of treatment, ill duration, the duration leprosy type and treatment with defect occurrence in leprosy client. WHO (2000) compiling an action to prevent the condition of physical handicap and limitation of leprosy client in society. Precaution emphasized at treatment of foot, treatment of hand, and treatment of eye (*Guide To Eliminate Leprosy A Public Health Problem WHO, 2000*).

This research identify about and hygiene situation of environmental physical around leprosy client. Amirudin (2000) done research of serologis at house contact and leper with leper in Ujung Pandang. Result of research show multibasiler contact, age more than 15 years and year of contact more than 2 years have very high anti-PGL-1 antibody titer for the medication of as effort kemoprofilaksis. Preventive measure can be conducted also with conservancy of patient house which is house contact. Djaiman (1999) studying about leper profile in District of Sarang, sub-province Rembang year 1996. Result of research shows about 29.5% other family member also suffer lifetime and leprosy remain together with other family which suffer leprosy with leprosy case that occurred in more than 3 months. And family client in exploiting health service relate to frequency and to long access the health service regularly. Result of research of Rachmalia and Sunanti (1999; in Hutabarat, 2008) indicating that role of health officer have high effect on to the adherence of medication within leper in sub-province Bangkalan.

### ***Expectation Client Leprosy***

Expectation to this own self represent desire which wish to be reached by client to condition of leprosy disease in this time and desire after ending a period to its medication to be powered in an activity of bevy. Leprosy client in this research is mustered in a place of that is Self Help Group (SHG). Ministry of Health Indonesia (2006) rehabilitating medical area can treat (care) with leprosy elimination program at the

same time through preventive program of disability, self help group or Self Care Group. Client Leprosy in this research follow SHG to get a service which do well by its situation pursuant to perception according to leprosy client. Bosch (2003) social organization in Spain emphasizing social aspect in leprosy disease promotion have been formed by the name of the Spanish Fontilles Association (SFA) in the year 1902. SFA in the year 2001 making a photographic exhibition program which narrate about social life of leper with theme "Approaching you, approaching them, approaching timely". Family support wanted by leprosy client in this research relate to function, source of, size measure, and social support type of instrumental informational goodness and or Leprosy client in this research wish its family member to always to support own self medication. Abraham and Shanley (1997) family support accepted by individual from others many depend on constructive social network. Social network represent defended relation with family member, neighbour and friend.

Fajar (2002) refer that there is family attitude influence which do not support to effort for regular medication and also take medicine regular at 100 leprosy client in Gresik. Family to motivate and give social support and also attention in the form of real attitude and feeling so that client can experience its medication. Result of research by Hutabarat (2008) showing 34 leper express role of family share 25 (73.5%) obedient take medicine, so that can be concluded by there is relation between role of family with compliance take medicine an leper in sub-province Asahan year 2007. This research identify that the desire relate to the nature of human being as social creature in braiding relation in society through acceptance of leprosy client in his social life. Arjuansyah (2001) evaluate execution of [is project of Leprosy Elimination Campaign (LEC) at leprosy disease eradication program in Sub-Province Banjar Province South Kalimantan year 1996–2001. Result of evaluation shows invention of passive patient after natural LEC of improvement compared with before LEC execution, make-up of invention of active patient, and improvement of recovering to mount. Result of research also shows the make-up of awareness of society about improvement and leprosy. In sub-province Sumedang year health of laboring

leper awareness program of society support acceptance of leprosy client in society

Some client in this research wish the existence of counseling of leprosy client and his problems on the chance of society become conscious and alert about leprosy and its danger. Sunanti (2000) evaluate leprosy disease treatment model in endemic area with social approach of culture in Banyuwangah sub-province Bangkalan year 1997–2000. Result of research shows, initially many natural constraints for example that angry society scorning at cadre if there is its family member who expressed as leper and there is ill part to be visited by cadre. Some the constraint can overcome, cadre more knowledgeable by the name of alone him as extension agent officer at patient and also society former leper, giving leprosy drug, observing to take medicine and look for new patient. Monitoring result of reporting and record-keeping from cadre works better.

This research identify health service which either from health officer will show behavior which are positive from leprosy client. Client will regularly medicated to CHC and follow activity related to its disease. Result of research of Rachmalia and Sunanti (1999; in Hutabarat, 2008) showing role of health officer vary having an effect on to adherence of client in medication in Bangkalan. Soemadipraja (1998) done research about factors related to CHC leprosy disease eradication officer performance in invention. Result of research indicate that most officer have ugly performance. This matter is supported by the existence of relation having a meaning between officer motivation, got by incentive in construction and officer and also got by support is officer with performance.

### **Limitation of Research**

Ability of researcher in dig of data through circumstantial interview less maximally related to depth of information and the duration of interview. All participant concerned in this research is MB type leprosy client. Researchers have limitations of information to get PB type leprosy client participant. Researcher has less access of articles and journal regarding research on treatment. Experience of leprosy client treatment in society and family, difficult so that compared to do dig which is researcher reflect the

condition of only in research location or also in other place.

### **Implication Research**

To serve treatment in community, compilation of treatment service model in leprosy risk population in society through integrative model health system, model self-supporting treatment, model treatment of family, and upbringing management model treatment of community is needed. This matter can be supported to pass the make-up interest through training of compilation and program approach of treatment upbringing cross culturally. The importance of adjacent model of leprosy client through house visit with usage of Operational Health relief fund CHC.

To the policy maker the existence of related/relevant health promotion of leprosy in society is needed in improving effort to listen carefully early history of leprosy, monitoring system and good evaluation in MDT logistics management through activity supervision, monitoring and evaluation is needed the existing activity of enabling self-supportive leprosy client so that productive, economic and can yield to pass inwrought skilled activity is needed.

The research of treatment hereinafter can be studied qualitative and quantitative regarding treatment of leprosy in society. Qualitative research like: phenomenology study about acceptance of client which have suffered leprosy during experiencing process rehabilitate in society, phenomenology study

experience of leprosy client in following activity of enableness like SHG in society, ethnography study experience of nurse in applying transcultural nursing at leprosy client at Madura culture and or Java. Quantitative Research like: effective treatment of husk, foot/feet, hand, and eye in preventing defect level and function trouble in leprosy client and effectiveness of guidelines about listening carefully early leprosy and or treatment of leprosy in invention of early case and leprosy prevention of leprosy in society.

### **CONCLUSION**

Experience of adult clients in experiencing treatment of leprosy in society is very unique and immeasurable. This matter relate to individual characteristic of leprosy client, family, and the client's environment remains. The unique experience of leprosy client experience the treatment start from response diagnosed by leprosy, own self picture and disease in distress of leprosy client. Everyday life pattern of client before diagnosed by has less ability in fulfilling elementary requirement and conduct treatment of own self causing occurrence of leprosy in society. Service type used by leprosy client even also vary influenced by local society culture so that will influence compliance level in management medication of MDT. Treatment done by family of leprosy client less optimal in executing duty of family, so that leprosy client have some expectation which client wish to fulfill by own, family, CHC and society.

### **REFERENCES**

- Abraham, C. & Shanley, E., 1997. Psikologi Sosial untuk Perawat. EGC. Jakarta.
- Amiruddin, M.D., 2000. Penelitian Serologis pada Penderita Kusta dan Kontak Serumah Penderita Kusta di Ujung Pandang. Diakses dari <http://digilib.litbang.depkes.go.id/go.php?id=jkpkbppk-gdl-res-2000-muhammad-1935-serumah&q=kusta>. Tanggal 30 Mei 2010.
- Arjuansyah. 2001. Evaluasi Pelaksanaan Proyek Leprosy Elimination Campaign (LEC) pada Program Pemberantasan Penyakit Kusta di Kabupaten Banjar Propinsi Kalimantan Selatan. Diakses dari <http://digilib.litbang.depkes.go.id/go.php?id=jkpkbppk-gdl-res-2001-arjuansyah-1925-lec&q=kusta>. Tanggal 30 Mei 2010.
- Azwar, A. 2000. Pengantar Epidemiologi. Jakarta: EGC.
- Badri, M., 2004. Perubahan Pemeliharaan Kebersihan Diri Santri Melalui Pemberdayaan Ustadz Di Pondok Pesantren Wali Songo Ngabar Ponorogo Tahun 2003. Diakses dari <http://www.top/unairthesis/ilmukesehatan/masyarakat/jiptunairgdl-s2-2004-badrimoham-1277.go.php.htm>. Tanggal 3 Mei 2009.

A Phenomenological Study on Leprosy Clients' Experience in Having Leprosy Treatment at Jenggawah Public Health Center Area at Jember, East Java, Indonesia 20 VOL. 3 (1) 2011 MALAYSIAN JOURNAL OF NURSING

Blashill, A.J., Wal, JSV., 2010. The Role of Body Image Dissatisfaction and Depression on HAART Adherence in HIV Positive Men: Test of Medication Model. Diakses dari <http://proquest.umi.com/pqdweb?index=0&did=1978930811&SrchMode=1&sid=3&Fmt=2&VInst=PROD&VType=PQD&RQT=309&VName=PQD&TS=1275566325&clientId=45625>. Tanggal 30 Mei 2010.

Boggild, A.K., Jason D.C., Jay S.K., Kevin C.K., 2004. Leprosy In Toronto: An Analysis Of 184 Imported Cases. Canadian Medical Association. Journal; vol. 6, pp. 170.

Bosch, X., 2003. Fontilles faces the future of leprosy. The Lancet. Infectious Diseases vol 3 April 2003. Diakses dari <http://www.Proquest.com/pqdauto/Nursing and Allied Health Source>. Tanggal 16 Desember 2009.

Britton, W.J., Diana N J Lockwood 2004. Leprosy. The Lancet; vol. 363, pp. 9416; de Groot, Janet M. 2002. The Complexity of the Role of Social Support in Relation to the Psychological Distress Associated with Cancer, Journal of Psychosomatic Research, vol. 52, pp. 277-278.

DeLaune, S.C. & Patricia K.L. 2002. Fundamental of Nursing: Standards and Practice (2nd ed). USA: Delmar/Thomson Learning.

Depkes RI., 2006. Buku Pedoman Nasional Pemberantasan Penyakit Kusta. Cetakan XV III. Departemen Kesehatan RI, Direktorat Jenderal Pengendalian Penyakit dan Penyehatan Lingkungan: Jakarta.

Dharamshaktu, NS., 1996. Control Efforts In India. World Health; vol. 49, 3; ProQuest Health and Medical Complete pg. 20. Diakses dari <http://www.proquest.com/pqdauto/Nursing And Allied Health Source>. Tanggal 16 Desember 2009.

Dinkes Jember, 2009. Kemiskinan Picu Meluasnya Penyakit Kusta Di Jember. Diakses dari [http://beritadaerah.com/artikel.php?pg=artikel\\_jawa&id=17449&sub=column&page](http://beritadaerah.com/artikel.php?pg=artikel_jawa&id=17449&sub=column&page) tanggal 16 Desember 2009.

Djaiman, S.P.H. 1999. Profil Penderita Kusta di Kecamatan Sarang, Kabupaten Rembang, 1996. Diakses dari <http://digilib.litbang.depkes.go.id/go.php?id=jkpkbppk-gdl-grey-1999-sri-37-leprosy&q=kusta>. Tanggal 30 Mei 2010

Ember, C.R., Ember, M. 2004. Encyclopedia of Medical Anthropology: Health and Illness in The World's Cultures. Kluwer Academic/ Plenum Publisher: New York.

Fajar, N.A. 2001. Analisis Faktor Sosial Budaya dalam Keluarga yang Mempengaruhi Pengobatan Dini dan Keteraturan Berobat pada Penderita Kusta (Studi pada Keluarga Penderita Kusta di Kabupaten Gresik). Diakses dari <http://digilib.litbang.depkes.go.id/go.php?id=jkpkbppk-gdl-res-2002-fajar2c-1309-kusta&q=kusta>. Tanggal 30 Mei 2010.

Gokhale, S D. 1996. Superstition and Prejudice. World Health; vol. 49, 3; ProQuest Health and Medical Complete pg. 10. Diakses dari <http://www.proquest.com/pqdauto/Nursing And Allied Health Source>. Tanggal 16 Desember 2009.

Gunadi, A. 2000, Kajian tentang Faktor-faktor Risiko Terjadinya Kecacatan pada Lepra di RS. Tugu Semarang. Diakses dari <http://digilib.litbang.depkes.go.id/go.php?id=jkpkbppk-gdl-res-2000-gunadi2c-1931-lepra&q=kusta>. Tanggal 30 Mei 2010.

Harjo. 2002. Faktor-Faktor yang Berhubungan Dengan Ketidakteraturan Berobat Penderita Kusta di Kabupaten Majalengka Tahun 1998- 2000. Diakses dari <http://www.digilib.ui.ac.id/opac/themes/libri2/detail.jsp?id=92369&lokasi=lokal>. Tanggal 29 Mei 2010.

Helvie, Carl O. 1997. Advanced Practice Nursing in The Community, New Delhi: SAGE Publication.

Hitchcock, J., Schubert, P., Thomas, S. 1999. Community Health Nursing: Caring in Action. NewYork: Delmar Publishers.

Hutabarat, B. 2008. Pengaruh Faktor Internal dan Eksternal Terhadap Kepatuhan Minum Obat penderita Kusta di Kabupaten Asahan Tahun 2007. Tesis. Sekolah Pasca Sarjana Universitas Sumatera Utara. Diakses dari <http://repository.usu.ac.id/bitstream/123456789/6740/1/057023003.pdf>. Tanggal 14 Mei 2010.

- Iskandar, F., et al. 1998. Hubungan antara Pemeriksaan Bakteriologis dan Pemeriksaan Serologis pada Penderita Kusta. Diakses dari <http://digilib.litbang.depkes.go.id/go.php?id=jkpkbppk-gdl-res-1998-iskandar2c-1929-serologis&q=kusta>. Tanggal 30 Mei 2010.
- Jacob, JT., Carlos FP. 2008. The Stigmatization of Leprosy in India and Its Impact on Future Approaches to Elimination and Control. *PLoS Negl Trop Dis* 2(1): e113. Dis2 (1) dari [http://www.ilep.org.uk/fileadmin/uploads/Documents/Infolep\\_Documents/Leprosy\\_Articles/Articles\\_2008/JACOB2008.pdf](http://www.ilep.org.uk/fileadmin/uploads/Documents/Infolep_Documents/Leprosy_Articles/Articles_2008/JACOB2008.pdf) tanggal 30 Desember 2009.
- Junaid, K. 2002. Kecacatan Kusta dan Determinannya di Wilayah Puskesmas Bantimurung Kabupaten Maros. Diakses dari <http://digilib.litbang.depkes.go.id/go.php?id=jkpkbppk-gdl-res-2002-kaya2c-1932-kecacatan&q=kusta>. Tanggal 30 Mei 2010.
- Kosasih, A. 1997. Faktor-faktor yang berhubungan dengan pengetahuan & sikap kepala keluarga dan tokoh masyarakat tentang kusta di Kabupaten Kuningan, Propinsi Jawa Barat, tahun 1996. Diakses dari <http://www.digilib.ui.ac.id/opac/themes/libri2/detail.jsp?id=79721&lokasi=lokal>. Tanggal 29 Mei 2010.
- Kumar, S. 1999. India Falls Short Of World Health Organization Leprosy Targets. *The Lancet*; vol. 353, pp. 9153; ProQuest Health and Medical Complete pg. 652. Diakses dari <http://www.proquest.com/pqdauto/Nursing And Allied Health Source>. Tanggal 16 Desember 2009.
- Ma'rufi, I., Keman, S., Notobroto, H.B. 2005. Faktor Sanitasi Lingkungan Yang Berperan Terhadap Prevalensi Penyakit Scabies. *Jurnal Kesehatan Lingunan* Vol. 2, No. 1, pp. 11–18.
- Matasik, M. 2002. Risiko Kontak Penderita Kusta, RFT dan RFC terhadap Kejadian Kusta di Wilayah Kerja Puskesmas Bantimurung Kabupaten Maros. Diakses dari <http://digilib.litbang.depkes.go.id/go.php?id=jkpkbppk-gdl-res-2002-mariana2c-1940-rft&q=kusta>. Tanggal 30 Mei 2010.
- Nicholls, PG., Wiens C, and Smith WCS. 2002. Delay in Presentation in the Context of Local Knowledge and Attitude Towards Leprosy: The Results of Qualitative Fieldwork in Paraguay. *International Journal of Leprosy and Other Mycobacterial Diseases*: Vol. 71, No. 3, pp. 198–209.
- Oesmasn, B. 1993. Faktor-faktor yang berhubungan dengan keteraturan berobat penderita kusta di Kabupaten Tangerang 1989–1991. diakses dari <http://www.digilib.ui.ac.id/opac/themes/libri2/detail.jsp?id=82181&lokasi=lokal>. Tanggal 29 Mei 2010.
- Omeri, A., Mcfarland, M. 2008. *Advances in Competary Transcultural Nursing Second Edition*. Content Management: Sydney.
- Pagolori. 2003. Analisis Faktor Risiko Reaksi Sesudah Pengobatan MDT pada Penderita Kusta di Kabupaten Gowa Tahun 2002. Diakses dari <http://digilib.litbang.depkes.go.id/go.php?id=jkpkbppk-gdl-res-2003-pagolori-1921-risiko&q=kusta>. Tanggal 30 Mei 2010.
- Pritchard, M.J. 1986. *Medicine and The Behavioral Science: An Introduction for Students of The Health and Allied Profesions*. Edward Arnold, London.
- Rachmalina. 1998. Penelitian Pengembangan Model Penanggulangan Penyakit Kusta di Daerah Endemis dengan Pendekatan Sosial Budaya. Diakses dari <http://digilib.litbang.depkes.go.id/go.php?id=jkpkbppk-gdl-res-1998-rachmalina-1133-kusta&q=kusta>. Tanggal 30 Mei 2010.
- Ruswan, H. 1997. Faktor-faktor yang Berhubungan dengan Kejadian Kusta pada Kontak Serumah di Kabupaten DT II Bekasi Tahun 1997. Diakses dari <http://digilib.litbang.depkes.go.id/go.php?id=jkpkbppk-gdl-res-1997-herry2c-1926-kontak&q=kusta>. Tanggal 30 Mei 2010.
- Soemadipradja, R.S.A. 1998. Faktor-faktor yang Berhubungan dengan Kinerja Petugas Pemberantasan Penyakit Kusta Puskesmas dalam Penemuan Kasus Kusta di Kabupaten Sumedang Tahun 1997/1998. Diakses dari <http://digilib.litbang.depkes.go.id/go.php?id=jkpkbppk-gdl-res-1998-r-1927-kasus&q=kusta>. Tanggal 30 Mei 2010.
- Stanhope, M., & Lancaster, J. 2000. *Community health nursing: promoting health of aggregates, families, and individuals*, 4th edition. St. Louis: Mosby-Year Book, Inc.

- Streubert, H.J & Carpenter, D.R. 2003. *Qualitative Research in Nursing. Advancing The Humanistic Imperative*. Third Edition. Philadelphia: Lippincott Williams & Wilkins
- Stuart. 2009. *Principles and Practice of Psychiatric Nursing 9ed*. St Louis: Elsevier Mosby.
- Sunanti, Z. 2000. Evaluasi Model Penanggulangan Penyakit Kusta di Daerah Endemis dengan Pendekatan Sosial Budaya di Banyuwangah Kabupaten Bangkalan. Diakses dari <http://digilib.litbang.depkes.go.id/go.php?id=jkpkbppk-gdl-res-2000-sunanti-1082-kusta&q=kusta>. Tanggal 30 Mei 2010.
- Suryanda. 2007. *Persepsi Masyarakat Terhadap Penyakit Kusta: Studi Kasus Di Kecamatan Cambai Prabumulih*. Tesis. Program Pascasarjana Minat Utama Perilaku dan Promosi Kesehatan Program Studi Ilmu Kesehatan Masyarakat Jurusan Ilmu- Ilmu Kesehatan UGM. Diakses dari [http://puspasca.ugm.ac.id/files/Abst\\_\(2880-H-2007\).pdf](http://puspasca.ugm.ac.id/files/Abst_(2880-H-2007).pdf) tanggal 30 Desember 2009.
- Suhariyanto, B., 2005. Kusta di RSUD Dr. Subandi. *Jurnal Berkala Ilmu Penyakit Kulit dan Kelamin* vol. 17 No. 1.
- Swanson, J.M., Mary A.N. 1997. *Community Health Nursing: Promoting The Health of Aggregates*. 2nd Ed. Philadelphia: W.B. Saunders Company.
- Snyder, Mariah., Ruth Lindquist. 2002. *Complementary/Alternative Therapies in Nursing (4th ed)*. New York: Springer Publishing company.
- White, C., 2008. Iatrogenic Stigma in Outpatient Treatment for Hansen's disease (leprosy) in Brazil. *Health Education Research*. vol.23 pp. 25-39.
- Wokaunn, M.,Ivan Juric, Zarko V. 2006. Between Stigma and Dawn of Medicine: the Last Leprosarium in Croatia. *Croat Med J*. vol. 47 pp. 759-66.
- Zulkifli. 2003. Penyakit Kusta dan Masalah Yang Ditimbulkannya. <http://www.usu.ac.id/digital/library>. Diakses pada 20 Pebruari 2009.