A STUDY OF THE LIVED EXPERIENCES OF PEOPLE IN A LEPROSY COLONY OF DELHI

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MASTER OF PHILOSOPHY

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CERTIFICATE

This is to certify that the dissertation titled, *"Study of the lived experiences of people in a Leprosy colony of Delhi"* is submitted by Neha Dwivedi in partial fulfilment of the requirements for the award of the degree of *Master of Philosophy (M.Phil)* of this university in her original work. This dissertation has not been submitted for any other degree of this university or any other university. We recommend that this dissertation be placed before examiner(s) for evaluation.

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NEVER, NEVER AGAIN I CALLED ANYONE A 'LEPER'

He limped towards me, half clad in a
tattered lungi,
fingerless hands holding a treasured
pack to his bosom –
bits of mouldy bread scooped from the
city's garbage bins.
Wounds, with dried up puss and blood
made him mean to my eyes.

Too coarse a person for me to accept –
he, a leprosy affected one!!
Insensate dusts of disgust blinded my
eyes;
I turned my face away, and called out,
"leper, leper, get away from me."

The word 'leper' – that battered his self-
esteem!
Clouds of shame and self-pity swathed
his being;
gloom left its solitary trail on his
piteous face,
dark spectre of self-contempt froze
there.
It made him less than a human being,
an outcast – his demeanour told me.

Oh, what disgrace the word 'leper'
carries –
loaded, indeed, with stigma's
debilitating curse!
The 'L-word' kills, it degrades, it
demeans
it dehumanizes – one ceases to exist at
all!!

I saw his pain – the pain of humiliation,
it stirred my inner being.
His wounded look hounded my
conscience.
I realized, calling someone a 'leper' is
cruel -
more cruel than stoning him to death!

I took his fingerless hands in my hands,
and said "Sorry, brother."
I saw the glimmer in his eyes – the joy
of acceptance.
His face beamed, its brightness
lightened up my rueful soul.

That day onwards, I never called
anyone a 'leper'.
I realized, calling someone a 'leper' is
cruel -
more cruel than stoning him to death!

- Jacob Oommen

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ABBREVIATIONS

ANCDR	Annual new case detection rate
BPL	Below poverty line
CBO	Community based organization
DHS	District health society
DANIDA	The Danish International Development Assistance
DPMR	Disability prevention and medical rehabilitation
GoI	Government of India
HDI	Human development index
IEC	Information, education and communication
ICCPR	International covenant on Civil and Political Rights
ICESCR	International Covenant on Economic, Social and Cultural Rights
ILEP	International federation of Anti Leprosy associations
IDEA	International Association for Integration, Dignity and Economic advancement
MB	Multi-bacillary leprosy
MCD	Municipal Corporation of Delhi
MDT	Multi drug therapy
MoHFW	Ministry of health and family welfare
NGO	Non Government Organization
NTD	Neglected tropical diseases
NLCP	National leprosy control programme
NLEP	National leprosy eradication programme
NRHM	National rural health mission
NLR	Netherlands leprosy relief foundation
PB	Pauci-bacillary leprosy
SLO	State Leprosy Officer
SET	Survey, education and treatment
TLM	The Leprosy Mission Trust, India

TCR	Treatment completion rate
UDHR	Universal declaration of human rights
UNHRC	United Nations human rights council
UNESCO	United Nations educational, scientific and cultural organization
WHO	World health organization
WER	World epidemiological record
WB	World Bank

"Loneliness and the feeling of being unwanted is the most terrible poverty".

Mother Teresa

CHAPTER 1: LITERATURE REVIEW

Present chapter on review of literature begins with a general overview about leprosy[1] as one of the neglected tropical diseases (NTDs) followed by an overview of the disease in colonial and post independent India. A brief highlight about global and national leprosy situation is also given in order to understand magnitude of the problem at present. Followed by this there are brief sections related with various life domains/events in the lives of people affected with leprosy. This includes migration, socio-cultural perceptions and religious beliefs about the disease, gender and its interlinkages with leprosy, social determinants of health, social support network, medical pluralism and pattern of resort in health experiences of people affected with leprosy, interface between begging and leprosy. A review of literature focussing on various dimensions of stigma and its impact upon people affected with leprosy along with conceptualization of dignity by them is also presented as a part of this chapter.

Review of literature was undertaken in two phases. One round was done right at an initial time before and during the fieldwork. Followed by this based on insights from fieldwork and kind of data available literature reviewed was further fine tuned. During analysis some new themes also emerged which were further incorporated at a later stage.

Literature available in the domain of medical anthropology, medical sociology, health geography, medical history, public health has been referred which is directly or indirectly related with leprosy. Work of both foreign and Indian scholars has been used for reference. Wherever required newspaper items and organizations reports are also referred. An attempt has been made to draw from a range of work in order to render a sound understanding to our empirical work.

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[1] For disease etiology refer annexure.

1.1 LEPROSY: ONE OF THE 13 NEGLECTED TROPICAL DISEASES (NTDs)

Hotez.P et.al. (2006) writes about the identification of a select group of 13 tropical infections[2] as NTDs by World Health Organization (WHO). One of them being leprosy is the subject matter of present empirical work. It is interesting to note the nomenclature of group of these diseases as 'tropical' and 'neglected'. As national public health priorities, NTDs including leprosy typically maintain a low profile and are often left out in mainstream public health agendas. While many of these diseases do not directly cause high rates of mortality, they contribute to an enormous rate of morbidity and a drastic reduction in income for the most poverty-stricken families and communities. These diseases are often found in impoverished populations living in marginalized and poorer areas. And often there is separation of the disease from its socio-cultural-economic milieu (Holveck.CJ et.al. 2007). NTDs are said to strike the world's poorest people living in poorer areas of countries in Sub-Saharan Africa and Asia. Remme et.al. *in* Jamison DT, Breman JG, Measham AR et al (2006; 433) (*Ed*) categorically states that *tropical diseases (or diseases of poor) are infectious diseases that are found predominantly in the tropics, where ecological and socioeconomic conditions facilitate their propagation.* Today increasingly 'geographical explanation in association with disease' is being seen as a dominant explanation rather than looking for causation links ingrained in socio-economic-cultural situations. This aspect is discussed further in the literature review.

1.2 LEPROSY IN COLONIAL INDIA

History of leprosy has long existed in Indian sub-continent but here the focus in on history of leprosy in British India because of some direct ramifications of the same in present day times. A very intensive work about colonial history of leprosy in India has been presented by historical narrative of medical historian Jane Buckingham.

Throughout 19th century various humoral understandings about leprosy gradually gave way to various postulations and disease models which were based on morbid anatomy, physiopathology and bacteriology (Robertson.J 2003). Discovery of *M.leprae* in 1873 by Hansen and understanding based on the same seeped down in India quite fast. As a

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[2] Buruli ulcer, Chagas disease, cholera, dengue fever (including dengue haemorrhagic fever), dracunculiasis, lymphatic filariasis, human African trypanosomiasis, leishmaniasis, leprosy, onchocerciasis, schistosomiasis, soil-transmitted helminths and trachoma

result by 1883 Carter, who was principal authority of leprosy in India, was able to provide his illustrations of bacilli discovered in a leprous nodule (Buckinghm.J 2002:15). Carter was able to bring in a convergence between different models of the disease prevalent at that time (Robertson.J 2003). Nation-wide decennial census was also initiated in 1871 with subsequent censuses in 1881, 1891, 1901. Enumerators were asked to make entry of leprosy affected populations as 'lepers'. 1891 census endorsed assertion made in 1871 census that leprosy existed in every block of each district. It was also found that leprosy was more common in dry districts with high seasonal rainfall (Buckingham.J 2002: 21-22). These censuses only reinforced widespread existing fear about the spread of leprosy among populations' especially imperial elite cadres. Need for immediate mechanisms to curb it were articulated. Timing of these censuses was such that during those periods etiology of leprosy was a major controversy with various propositions. But evidence generated was such that all efforts to clarify disease etiology and estimates about contagiousness by means of statistics were only endowed by the desire to justify pre-conceptions about the disease and its sufferers. In spite of the realization that these censuses were important in leprosy control measures, there was no fruitful utilization of the same in India (Pandya.S 2004).

After the death of Belgian missionary priest Father Damien as a tribute to him National leprosy fund was created on 17 June 1889 presided over by Prince of Wales. Here it is important to understand that Europeans often described the most dramatic forms of disfiguring leprosy, evoking fear of an 'imperial danger': leprosy reaching the British Isles[3]. The public pressure on the colonial government for the segregation of people afflicted with leprosy lead to sending of Leprosy Commission (comprising both physicians and administrators) by British Government to India in November 1890 to investigate and analyse the situation. It was found out from the investigation of Commissioners that '*neither compulsory nor voluntary segregation would at present effectually stamp out the disease, or even markedly diminish the leper population, under the existing conditions of life in India'*. In spite of that decision to stick with segregation of leprosy population was upheld by National leprosy fund (Robertson.J 2009). The commission's report in 1891 concluded that ''*the amount of contagion which exists is so*

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[3] Three major events were responsible for this growing fear of leprosy and its contagiousness among people. First leprosy census of 1872 reporting a PR of 54/10,000 cases, Discovery of M.leprae in 1873 as agent causing leprosy infection and death of Father Damien, Belgian priest in 1889 while serving people affected with leprosy in Hawaii

small that it may be disregarded'. Initially, the colonial government accepted these findings but, under increasing popular pressure from England and within India, findings were discarded soon.

In the 19th century amidst paramount pressure from European and Indian elites, representation of leprosy as a threat to British Empire and lobbying by medical fraternity eventually lead to introduction of Leper's act[4] in 1898 marking the beginning of confinement of people affected with leprosy. This act was actually an incremental outcome of various events and inter-connected interests developed during the century. Selectivity in filtering out and segregating leprosy affected populations was no new phenomenon even in colonial times. Implementation of leper's act was at the will of district authorities and targeted at removal of 'heinious leprous beggars' believed to be a cause of public nuisance. One of the principal consequences of leper's act was about costs incurred on leprosy care rather than conditionalities of leprosy control. Under section 3 of act, there was a provision where local governments could declare any place to be a 'leper asylum' for the purposes of this act. Segregation and care of leprosy sufferers was chiefly endowed as responsibility of private institutions with grant in aids support. A new relationship started to emerge with delineation between the Mission of lepers and the government. By the turn of 20th century, care and treatment of leprosy sufferers became the responsibility of the Mission. A clear transfer from local state authorities to religious private philanthropy was observed. Notions of spiritual welfare were introduced with missionary involvement (Buckingham.J 2002: 184-188).

Leprosy act was repealed in 1983 after the advent of effective Multi Drug Therapy (MDT) for leprosy and intense advocacy efforts. The establishment of the Indian Council of the British Empire Leprosy Relief Associated in 1925 (Renamed as Hind Kushth Nivaran Sangh in 1947) laid the foundation of organised leprosy work in India (Jacob.JT. and Carlos.PF. 2008, National Leprosy Eradication Programme, NIHFW n.d.).

1.3 LEPROSY PROGRAMME IN POST INDEPENDENT INDIA

Efforts to control the disease have marked Indian government's initial approach, starting in 1955 with the creation of the National Leprosy Control Program (NLCP) and introduction of Dapsone monotherapy based domiciliary treatment. Treatment was

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[4] Prior to this a resolution was passed in 1888 with enactment of leprosy bill on 15 March 1889.

through vertical units implementing survey education and treatment (SET) activities based on SET pattern devised by Dr Wardekar in 1952 (Central Leprosy Division, 2012). It was as late as 1970s when MDT based cure was identified and came into global use by 1982, after recommendations by WHO study group in Geneva in October 1981 (National Leprosy Eradication Programme NLEP n.d.).

In 1981 then Prime Minister Indira Gandhi took a major initiative to mobilise the bureaucracy, leprosy experts and science advisory committee and WHO to draw up a programme for action to 'eradicate leprosy by 2000 AD'. Ineffectiveness of NLCP in achieving desired epidemiological goals was very evident by this time. Major reasons for the failure of NLCP have been that the conceptualization of programme was not based on any sound scientific methodology applicable and epidemiologically effective solution with an absence of any kind of inter-disciplinary inputs (Rao KV 1992). Based on Swaminathan Committee suggestions (constituted in 1981) and recognising the failures of NLCP, a marked shift in strategies from control to eradication (and then later elimination) was made with introduction of National leprosy eradication programme (NLEP) in 1983 and a thrust on curative aspect of the programme focussing on treatment with MDT[5] was laid. Major strategies of NLEP which were devised are as follows (National Leprosy Eradication Programme, NIHFW n.d.)

- Early detection through active surveillance by the trained health workers
- Regular treatment of cases by providing MDT at fixed in or centres a nearby village of moderate to low endemic areas/district
- Intensified health education and public awareness campaigns to remove social stigma attached to the disease
- Appropriate medical rehabilitation and leprosy ulcer care services.

Since 2005 all external funding was withdrawn and NLEP has been a centrally sponsored programme of Ministry of health and family welfare (MoHFW), Government of India (GoI) and is headed by deputy director general of health services (leprosy)[6] and is under administrative control of the directorate of general health services, GoI. Since health is a state subject so plans and strategies formulated centrally by NLEP are implemented at programme level by states and union territories individually. NLEP is

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[5] MDT was recommended by WHO in 1981 for Leprosy cure.

[6] Currently Dr CM Aggarwal is Deputy director general of health services (leprosy)

also supported by various international actors like WHO, International federation of anti leprosy associations (ILEP- consortium of 16 organizations), Novartis, Nippon foundations, Sasakawa Memorial health foundation and World Bank (in the past) (National Leprosy Eradication Programme NLEP n.d).

Undoubtedly planning of programmes and policies in India in relation with leprosy has been immensely affected with various international actors and globally set priorities. This is evident from a brief discussion below.

In May 1991, fourth World Health Assembly adopted a resolution in Geneva to eliminate leprosy as a public health problem by the year 2000 AD. Definition of elimination was defined as attaining a prevalence level of less than once case per 10,000 populations. Member states were urged to strengthen political commitment to achieve elimination of leprosy at country levels. As a result of this resolution and the clear mandate stated in it global free supply of MDT drugs was achieved through WHO (World Health Assembly Resolution, 1991). Here the major goal set was 'elimination of leprosy by 2000 AD in response to the global deadline defined by WHO. The *strategic plan for leprosy elimination 2000-2005* called for commitments by leprosy endemic countries and thus mobilizing support to ensure availability and accessibility of leprosy services[7] to all the people affected with it. There were intensive mass campaigns globally and a widespread reduction of the global prevalence of leprosy cases registered at health facilities (Pannikar V 2009, WHO 2009). Having missed the previous deadline of 2000, a new target was set in 2001 for remaining 14 countries including India – 'eliminate leprosy by 2005'. Followed by elimination of leprosy globally in 2005 including India (except for few countries) a *new global strategy was devised for further reducing the burden of leprosy and sustaining leprosy control activities 2006-2010.* Here the main component envisaged was: ensuring the sustainability of the programme by promoting integration with the general health system. In 2009, WHO's *enhanced global strategy for further reducing the disease burden due to leprosy 2011-2015 through the updated operational guidelines* was devised. This strategy is based on principles of morbidity control which implies timely detection and cure of cases detected with effective chemotherapy. Here the focus is sustaining on the efforts made

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[7] Leprosy services include diagnosis, treatment with multidrug therapy, patient and family counselling, community education, prevention of disabilities/impairments, rehabilitation, and referral for complications.

so far and attempt to further reduce disease burden in all endemic countries and communities. There has been a thrust throughout on maintaining quality of services. A global target to monitoring progress is also envisaged. It is aimed to globally reduce the rate of new cases with grade-2 disabilities per 100,000 population by at least 35% at the end of 2015, compared to the baseline at the end of 2010. It is assumed that setting a global target based on reducing the occurrence of new cases with grade-2 disabilities will give impetus to the implementation of activities that will reduce delays in diagnosis and initiation of treatment with MDT. This will in turn have an impact on reducing the occurrence of new cases in the population (Pannikar V 2009, WHO 2009).

Call for global elimination of leprosy including in India also invited huge amounts of international funding. First World Bank (WB) supported project was introduced in 1993 and continued till March, 2000. In the second phase, support was continued for a period of three years from 2001-02 to December, 2004. Since January 2005 NLEP is centrally sponsored with additional programme support received from ILEP organizations and WHO. Novartis foundation supplies global stock of free MDT drugs. From 1986-2003 The Danish International Development Assistance (DANIDA) supported Indian national leprosy programme (Disability prevention and medical rehabilitation-Guidelines, 2012).

During 9th five year plan (1997-2002) of India, horizontal integration of vertical programmes was envisaged including NLEP. It was proposed that leprosy services be provided through the primary health care infrastructure and integration of all Information, Education and Communication (IEC) related activities. National health policy which came up in 2002 during this plan period also envisaged leprosy elimination by 2005 in response to internationally set commitments. Case detection was intensified with wider MDT coverage, laboratory services were strengthened, surveillance systems for monitoring time trends were established and there was an implementation of modified leprosy campaign launched in 1997 during this plan period. Target set was less than 1 prevalence rate per 10,000 populations (Ninth Five Year Plan 1998-2002).

In 2004 leprosy programme was integrated with general health services. This was during 10th five year plan (2002-07). In 2005, National rural health mission (NRHM) was launched which also reiterated integration of vertical health programmes including

NLEP. Leprosy elimination declaration was also made during this plan period in the year 2005. Disability prevention and medical rehabilitation (DPMR) component was introduced in 2006 (Tenth Five Year Plan 2002-2007). Even in 11th five year plan emphasis was laid on maintaining achieved PR below one and continuing with integrated component of the programme with no vertical structures below district level (Eleventh Five Year Plan 2008).

But this glorious declaration made by India in 2005 of having eliminated leprosy with a nationwide prevalence of 0.95/10,000 population as on 31 December 2005, needs to be deeply scrutinized (Staples.J 2007). Declaration is accompanied with much of the criticism regarding accuracy and choice of target parameter (Feenstra.P 2003). In 2010-11, among global 2.28 lakh cases of leprosy, India had a share of 1.26 lakh cases (55.2%). 14 States have shown an increase in the number of new cases detected in 2010-2011 with over 12,000 new cases among children. This signifies a latent reservoir of leprosy bacillus among populations and resurgence of the disease in spite of elimination in 2005. Although India's current prevalence rate is 0.69 per 10,000 populations but yet many districts have reported high incidences of leprosy cases. Between 2010 and 2011, 77 districts across India reported more than one leprosy case per 10,000 population (Press Trust of India, 27 July 2013). Bihar, a high endemic state accounts for more than 14% of new cases detected with a PR of 1.12 per 10,000 populations (Sinha.N, 6 February 2012).

Interestingly even in 12th plan document (2012-17) it is clearly stated that India bears a high proportion of global burden of leprosy which comes to 56% (Twelth Five Year Plan 2013;7). One of the key outcome indicators set for this plan is prevention and reduction if burden of leprosy with setting up of state wise and national targets. Emphasis is further laid on district level activities to achieve elimination status and prevention of disabilities and deformities. A special action plan has been launched in 2012 for 209 high endemic districts in India.

1.4 CURRENT LEPROSY SITUATION: GLOBALLY AND NATIONALLY

In spite of national and sub-national campaigns in most endemic countries, new cases continue to occur in all leprosy endemic countries and high burden pockets against a background of low burden backgrounds (Weekly epidemiological record WER 2012:317). As per the records, the number of new cases detected during the year 2011, as reported by 105 countries, was 219,075 (case detection rate[8] was 4.06). The registered prevalence globally at the beginning of 2012 was 181,941 (prevalence rate[9] of 0.34). South East Asia region has reported the maximum with 117,147 cases registered and a prevalence rate of 0.64 registered in first quarter of 2012. Number of new cases detected has been also maximum in this region (160,132) with a recorded case detection rate of 8.75 in the year 2011 (WER 2012).

Except for Africa and Americas region, new case detection annually continues to increase globally. But in Africa this necessarily does not imply actual decline in number of cases, there are various logistical factors which also play its role in actual case reporting. In the context of South East Asia, number of new cases detected in 2004 were 298,603 which declined to 201,635 in the year 2005. By 2010, it was recorded as 156,254 and in the year 2011 decline was to a figure of 160,132. Thus, from 2004 to 2011 there has been a total decline of 138,471 cases which is still the highest number among all five regions of WHO. During this same period a global decline of 188,716 cases has been recorded (407,791 in 2004 and 219,075 in 2011). In terms of number of cases of leprosy (rate/100,000 population) with grade 2 disabilities detected among new cases, South East Asia region of WHO is at the top with 7095 cases (0.39) which is followed by African region recording 1446 cases (0.36) in the year 2011. In South East Asia region this has remained almost unchanged from 2005 with 6209 cases (0.37) and maximum being in 2009 with 7286 cases (0.41) (WER 2012).

Considering a national picture, India has shown a very slow decline in new case detection since the year 2006, immediately after the year of elimination declaration. India is responsible for a contribution of 58% new cases detected in the year 2011, followed by Brazil (16%) and Indonesia (9%). India has been one of the 18 countries which have reported more then/equal to 1000 new cases during 2011. India has been at the top with a record of 127,295 new cases followed by Brazil with 33,955 new cases and Indonesia with 20,023 cases. India has been at all time among all 18 since 2004 till now. As per these records for India, 83,187 has been registered prevalence at the end of first quarter of 2012 with 127,295 new cases detected in 2011, 63,562 new cases of

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[8] The case-detection rate is the number of cases/100 000 population.

[9] The prevalence rate is the number of cases/10 000 population.

multi-bacilliary (MB) leprosy, 47,111 females and 12,305 children among new cases, 3,834 new cases of grade 2 disability and a total of 690 cases of relapse. 95.28% cure rate was registered for pauci-bacilliary (PB) cases in 2010 and 90.56% was cure rate registered for MB cases in 2009 (WER 2012).

If one looks at district wise data for annual new case detection and prevalence (NLEP, March 2013) a wide disparity across within states and across district is seen. In spite of very high ANCDR across certain districts government is still able to stick to a figure of less than/equal to 10 (per 100,000 population) with few exceptions. This is quite ironical also because of the way jugglery with numbers one gets to observe after looking at government data. In the table 1, data for the year 2012-2013 (NLEP) is shown with number of new cases detected, ANCDR and prevalence rate for endemic leprosy states in India.

Table 1 NLEP Data for selected Indian states (2012-13)

State	Number of new case detected in 2012-13	ANCDR/100,000 (2012-13)	Prevelence Rate per 10,000 population (as on March 2013)
Uttar Pradesh	24,222	11.70	0.72 12 districts>1.0
Bihar	22,0001	20.27	1.20 20 districts>1.0 3 districts >2.0
Maharashtra	18,715	16.17	1.09 10 districts>1.0 2 districts>2.0 3 districts>3.0
West Bengal	11,683	12.46	1.05 5 districts>1.0 2 districts>2.0 1 district>3.0
Gujarat	9,019	14.42	0.96 2 districts>1.0 8 districts>2.0
Andhra Pradesh	8,295	9.59	0.61 1 district>1.0
Orissa	8,226	19.10	0.98 9 districts>1.0 4 districts>2.0
Chhattisgarh	8115	30.50	2.13 9 districts>1.0 5 districts>2.0 3 districts>3.0
Madhya Pradesh	6400	8.58	0.72 7 districts>1.0 2 districts>2.0
Jharkhand	3691	10.75	0.66 3 districts>1.0
Tamil Nadu	3550	4.78	0.39 1 district>1.0

Source: National Leprosy Eradication Programme 2012-13

Thus, one can clearly see that in spite of leprosy elimination declaration by India in 2005, in the post elimination era there has been a consistent rise in number of new cases being detected annually and prevalence rate higher than 1 in many districts of highly endemic states. Despite the claimed reduction in prevalence, India continues to be one of the endemic countries (those with more than 1000 leprosy patients per year). India registered 134,000 new cases in 2010 accounting for more than 54% of cases globally; one every five minutes (Lepra India, n.d;a). Still there are 'pockets' of leprosy even in states where it has been declared eliminated at a state level. One of the factors responsible for this is long incubation period of the disease and relatively higher prevalence of leprosy in certain areas of the country as leprosy is known to be a pocket disease.

1.5 LIFE EXPEREINCES OF PEOPLE AFFECTED WITH LEPROSY

One of the research objectives of the present study is to see various life experiences of people affected with leprosy in the limelight of their disease. As it is shown through literature review and even field situations, this experience certainly cuts across caste, class, religion and gender. An attempt has been made to review existing literature and related literature in subsequent sections on various themes like migration, socio-cultural perceptions and religious beliefs about the disease, inter-linkages with gender, social determinants of leprosy, begging, social support network and leprosy etc. Literature has been also reviewed in relation with health and treatment experiences of people affected with leprosy. This includes medical pluralism and pattern of resort. This also extends to a section on stigma wherein experiences of stigma of people affected with leprosy in health settings has been also reviewed.

1.5.1 LEPROSY AND MIGRATION

Linkages between migration and leprosy is not new wherein people affected have been found to migrate to cities or different regions or even countries for various reasons. It not only contributes to new case detection rates but also to an increased prevalence of leprosy in a given population (Chudasama RK et al 2007, Samuel.P et al 2012). Moreover, migration to a new place also bears important implications onto human rights of affected population. They face multiple problems of varied nature and negative image ingrained in public psyche because of existing health condition (Soultar D 2010, White.C 2010). White.C (2011) in her work in an international context writes about increased difficulties in diagnosis and communication about illness and treatment on account of the circumstances of immigration in combination with social-cultural-linguistic barriers between people affected and healthcare providers.

Study by Aasilian A et.al. (2005) done in Isfahan province of Iran clearly showed that all new cases detected were migrants from outside the province. Shen J et.al. (2010)

through their work show that among newly detected leprosy cases, a small proportion was of migrants. Fisher et.al. (2008) did an observational study in Bangladesh where spatial distribution of leprosy cases during last 15 years of Leprosy control programme was done. It was found out that the risk of leprosy was maximum within one kilometre radius of town centres which decreased with increasing distance from the centre. There have been studies on internal migration as well which support the same argument made above. Chudasama RK et.al (2007) did a study in Surat District wherein they found an increase in leprosy cases in the district from 2001 to 2006, due to migration. Samuel P et al (2012) did a study which reiterated the fact that proportion of migrants among the number of new cases has been increasing over the years.

In cross country immigration context, it is clearly established that most of the leprosy cases in non-endemic countries are contributed by immigrants from endemic regions of the world and leprosy cases in a particular country is a reflection of immigration patterns (Levis WR et.al 1982, Kandari-Al.S et.al. 1990, Taylor R et al 2003, Boggild AK et.al 2004, Khan SA and Ghosh P 2005, Soutar.D 2010, Levis MR et al 2011, White.C 2010, 2011, Qubati-Al-Yasin 2012).

It is also important to understand the link between migrant's socio-economic position and ill health in the broader context of host migrant relationship. There are multiple trajectories through which socially driven health inequalities internal to particular groups (here people affected with leprosy) are compound with external ones to influence health (Prost.A 2008). In the case of people affected with leprosy, socio economic deprivation along with emblematic character of the disease impacts their access to resources, healthcare and conceptualization about self. Migration by people affected with leprosy contributes to building up of a new form of social solidarity which is determined and shaped because of a 'commonly shared leprous identity'.

There are both 'push' and 'pull' factors which play a significant role in migration of people affected with Leprosy. Moreover, in the case of women there is a gendered aspect as well to migration- she has to migrate most often because of marriage along with her husband (Samuel.P et al 2012). Search of a livelihood/job, availability of better treatment facilities and other essential services, anonymity of living, marriage prospects count as some of the pull factors. This is in juxtaposing to 'push' factors which compel people affected with Leprosy to migrate elsewhere. Push factors comprises of stigma (self and enacted both)[10], refusal of employment, turning away by family etc (Samuel.P et al 2012). Stigma has been known to play an important role in self-imposed withdrawal from the community and complete banishment from family and social networks especially in those countries where leprosy is endemic (Heijnders ML 2004, Barrett.R 2005). These push factors actually lead to a forced ghettoisation and formation of leprosy colony comprising of people with a similar identity (Kaur and van Brackel, 2002, Chakraborthy A, Mahatao M and Rao PSS 2006). Facilities provided in a particular city and government schemes and policies also play a crucial role in attracting people from all over. Dambalkar K, Vashist RP and Ramesh V (1995) write that in Delhi[11] range of facilities provided, concessions given and pension scheme to people affected with Leprosy made migrants to stay back permanently even after they completed their treatment. Brettel as cited in White.C (2011: pg 152) has noted that the experiences of an immigrant group varies widely depending on the city or region to which they migrate, even within the same country. Transportation options, employment opportunities, healthcare availability, and cultural/ethnic makeup of an urban or rural area can all affect the experience of immigration and may directly or indirectly affect entire experience of illness for immigrants. The presence of a community of people of the same national background could provide social networks and a support system, though preconceived ideas about the disease within that community might also be present.

1.5.2 SOCIO-CULTURAL PERCEPTIONS AND RELIGIOUS BELIEFS ABOUT LEPROSY AND PEOPLE AFFECTED

Leprosy is one of the most stigmatized and feared disease since time immemorial in site of medical advancements and effective treatment available in the 21st Century. Many myths, misconceptions and beliefs in grained in socio-cultural-religious milieu have shaped social image of a 'leper' and perceptions towards him/her.

In India, the Laws of Manu (1500 BC) mention various skin diseases translated as leprosy. The Laws prohibited contact with those affected by leprosy and punished those

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[10] Refer to literature review on stigma for an understanding about these terms.

[11] Exactly this has come out from field work as well. Where in people have migrated from different states like Tamil Nadu, Andhra Pradesh, Orissa, West Bengal, Karnataka etc and settled down in leprosy colonies in Delhi. There is regional segregation of each of these colonies. They have all the basic essential services, pukka house with land entitlement, Rs 1800 monthly pension, more charity and donation activities, better earnings prospects for their healthy dependents, good education is available for their children as compared to situations back home. These colonies are politically also quite active and a centre of attention by some or other political person.

who married into their families. India's *Sushruta Samhita* (600 BC) recommended treating leprosy with oil derived from the chaulmoogra tree; this ineffective prescription remained a mainstay of treatment until the introduction of sulfones (Jacob JT, Franco-Paredes C 2008 as cited in Awofeso.N 2011). In Christianity, Biblical reference to a leper and his healing by Jesus is no new to the domain of Leprosy. Many of the social responses to people with the disease were based on biblical teachings. Bible alone makes about 50 references to the disease (Mac Arthur, 1953 as cited in Covey.H 2001). As per the law of Moses, this disease was a result of sins and the person suffering was deemed to be heinous. Lewis 1987, as cited in Covey.H 2001, writes that 'Lepers' were perceived to be unclean. Leviticus 13: 44 – 46 states, "*Now whosoever shall be defiled with the leprosy, and is separated by the judgment of the priest, shall have his clothes hanging loose, his head bare, his mouth covered with a cloth, and he shall cry out that he is defiled and unclean. All the time that he is infected and unclean, he shall dwell alone without the camp.*" A leper was marked as an outcaste and socially ostracized. Al-Bukhari's Muslim Hadith (volume 1, 2.443) documented Prophet Mohammed's apparent dread of leprosy in his statement: "Escape from the leprous the way you escape from a lion" (Awofeso.N 2011).

Interestingly there are some local legends as well like in China and Africa where leprosy is associated with necrophilia and incest (Awofeso.N 2011). Leprosy was also believed to be a moral disease and linked with morality of an individual. Affliction with the disease implied punishment from God for one's sins and a warning to all living human beings (Brody, 1974; Richards, 1977 as cited in Covey.H 2001). Thus a mythological notion was attached to disease causation and consequences which not only created fear in the minds of people towards those affected but also acted as a check mechanism in reaffirming moral order of the society. A 'leper' was also believed to be a 'pervert' with heightened libido and sexual behaviours. There have been other myths as well which one often gets to hear even today while in the field. Like during Medieval ages[12] some people believed leprosy could be spread through the breath, thus people with the disease were only permitted to communicate when they were downwind (Brody 1974; Burt1982; Jacquart & Thomasset 1988 as cited in Covey.H 2002). There are various cultural beliefs associated with disease causation which have been

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[12] Undoubtedly these beliefs in the past contributed a great deal to formulation of various myths and misconceptions associated with Leprosy which is believed by people till today in spite of advancements in medical knowledge.

documented by Wong ML and Subramaniam P (2002;3): Punishments for sins , Immoral conduct e.g. sex with prostitutes, Bad blood/ unclean blood, Evil spirits/ Curse/Local charms/ Witch craft/ Breaking a taboo, God's will, Hereditary, Natural forces e.g. body humours, hot air, sea breeze, Food e.g. Hot/ cold, forbidden food, Under nourishment, Marrying/ having sex with a leprosy patient, Spontaneous appearance etc.

In her historical narrative, Buckingham.J (2002) writes that Siddha and Ayurveda system of medicine recognized 18 types of Leprosy which also comprised of psoriasis, leucoderma, syphilis amd morphoea as milder forms of leprosy. In the 16th C, syphilis was identified as a condition separate from Leprosy which lead to a dramatic decline in the number of people identified as 'leprous'. But yet rendering of an understanding based on association between sexual behaviours and leprosy continued which did label people as 'sexually immoral and perverts'.

Irrespective of medical opinions and advancements, leprosy is still one of the most feared diseases among masses. Immediate response upon seeing a 'leper' is fly or flight. This fear is because of two reasons: belief that it is contagious and social image of a 'leper' created on account of disability and disfigurement (Kopparty SN, Kurup AM and Sivaram M 1995). As cited in Covey.H 2002, Dols (1983) writes that most common social perception has been that people having leprosy should be feared. Opinion held about affected people during Medieval ages was carried forward even till late modern era where people with leprosy are seen as outcaste, untouchable, untrustworthy, wrathful, unclean, hopeless, and suspicious. To the medieval citizen, leprosy meant a long, disfiguring, and inevitable death. Given the perceived horrors of the disease, medieval citizens avoided contact those with the disease. Medieval citizens worried they could contract leprosy from associating with people with the disease and officials often made provisions in medieval law, such as prohibitions regarding property ownership (Covey.H 2002).

1.5.3 GENDER AND LEPROSY: UNDERSTANDING INTER-LINKAGES

Studies reveal a wide range of gendered social impacts on account of leprosy in the lives of those affected. Here an attempt is made to take recourse of gendered nature of experiences which people had on account of the disease rather than comparing experiences of men and women who are affected with leprosy. The social differences between men and women do interact with biological variables which is important to understand. There are different experiences of leprosy affected men and women which bear a gendered connotation (Rao.S et al 1996, Vlassoff.C, Khot.S and Rao.S 1996). Existing gender inequalities in a particular society impact to a great deal health outcomes among those affected especially in the case of women. The very nature of leprosy which is highly stigmatized can have serious impact on these existing gender inequalities. Manifestations of these inequalities have been seen in terms of rates of case detection, treatment adherence and reversal reactions among leprosy patients (Le Grand A 1997). Dominant patriarchal nature of Indian society gives a perfect matrix to analyse gender differentials in relation with health outcomes (here on account of Leprosy). Gender disadvantages created in mental, physiological, socio-economic spheres of life increase manifold taking into account developing country perspective wherein men and women have different socially ascribed status (Naik SS, Hambarde PS, Desai AN 1991; Kaur.H and Ramesh.V 1994; Le Grand.A 1997; Barrett.R 2005; Try.I 2006; Varkevisser CM et al 2009). 'Double jeopardy' has been the term coined to this situation of gendered vulnerability created among women on account of leprosy in developing countries (Ulrich.M et al 1993; Rao.S et al 1996; Morrison.A 2000). Tolhurst.R et.al. (2002) very appropriately wrote which in fact summarizes the whole idea as well

> '*Gender identities, status, roles and responsibilities influence vulnerability to disease, access to health care, and the impact of disease for women, men, girls and boys. Women's and men's roles affect their risk of infection with specific diseases, whilst gender relations influence their ability to protect their own health. Gender differences in access to and control over resources, in decision making power in the household and in roles and activities can limit women's ability to access health care for themselves and their children. Gendered norms and identities influence both women's and men's willingness and ability to seek care. The social consequences of infectious disease are often more severe for women than for men, and illness imposes a particularly heavy labour burden upon women*'.

Gender differences among people affected with leprosy bears its outcome at two levels. Firstly, it is associated with treatment aspect wherein disavowal, concealment and consequent delay in diagnosis has been reported which in turn influences treatment seeking behaviour. Strategies of disavowal and concealment further the progression and spread of leprosy through late detection, under treatment and adherence to medical regime. It has been known that significantly fewer female cases than male cases are detected through voluntary reporting. (Mull et al 1989; Kopparty, Karup, and Sivaram 1995; TDR News 1997; Rao et al 1996; Barrett.R 2005). But regional differences in reporting by male and female also matter (Varkevisser CM, Lever P, Alubo O et al 2009). A study done in Nepal also established a significant association between treatment completion status and gender which depends on social status of male and female in respective societies. In this case it was higher for males (Kumar.R et al 2004).

Secondly, it is in terms of stigmatization process associated with the disease. Ulrich.M et al (1993) in their work state that women in leprosy-endemic areas of the world, with few exceptions, suffer from marked economic and social dependency and inferiority which is heightened furthermore by the social stigma associated with leprosy. Grand.Le.A (1997) categorically states that existence of gender inequalities and affliction with highly stigmatized diseases like leprosy, can have a very significant impact especially on women's health. Dimensions of stigmatisation differ significantly for men and women, for a woman affected with leprosy chances of marriage are significantly reduced and possibilities of divorce/desertion are considerably increased. Men were more likely to divorce their spouses if they became ill, and to remarry (Awofeso.N 1995, Rao et.al. 1996). Stigma associated with the disease also affects treatment seeking behaviour of women especially in settings where culturally lower status of women is defined. It was found out that a sharp decline was observed in the number of registered cases among women aged 11-19 years, a period coinciding with the arrangement of marriage in India, followed by a sharp increase in female cases aged 20-35, compared to the number of cases among men (TDR News 1997). This is because of the fact that many parents keep their affected children, especially daughters, (for fear of not being able to marry them off) locked away from the public eye and many husbands are frightened and ashamed, because of the stigma of the disease, for their wives to be seen as 'lepers' (Lepra India, n.d.; b). Secrecy maintained at the time of marriage about hidden leprosy status of prospective bride or groom has been noted by Try.L (2006) as well because stigma of revealing the same not only affects marriage prospects of the girl and boy but also of other family members as well. In Goffmanian term 'courtesy stigma' plays out its role. Culturally located and stigma-based gender perceptions and consequent behaviours define the standards for men and women in terms of selecting marriage partners. Nature of relationships shared between the two plays an important role in such a context.

Rao.S et al (1996) identified distinct gender differentials in social impact of the disease. It was found out that initial delay in diagnosis of the disease was higher for females, and even after diagnosis females were found to be dependent on nonmedical treatment for longer durations. Interestingly, treatment compliance was more among women in comparison with men but advantage of regularity was outweighed by initial delay in diagnosis. Study also highlights one more gendered aspect impacted by the disease-social impact of the disease upon daily lives of those affected. It was found to be more severe for females than males because females suffered more isolation and rejection in daily life activities, such as, restrictions on participation in social events, touching children etc (Rao.S et al 1996, Zodpey S, Teary R, Salodkar A 2000). But indeed intense suffering is for both the sexes. Likewise, Vlassoff.C, Khot.S and Rao.S (1996) also point out marriage and family reactions as two major domains of social impact of leprosy. Both men and women are negatively affected by the disease but it is important to understand here that because of existing nature of relationships, impact is more severe among women. Mental suffering is much intense in the realm of deprivation from personal contacts in a domestic environment. Familial support is very critical in cure and treatment of leprosy, and this is even more critical for women, who often lack access to the variety of outside advice and assistance available to men[13].

Considering biology of the two sexes, women undergo physiological immune-suppression from ovulation until menstruation and in pregnancy until 6 weeks postpartum. This affects course of leprosy among pregnant and lactating mothers, which in turn affects health of the baby. In a cohort study by Duncan.ME, relapse, reactivation, and new leprosy peaked in the third trimester, dropping sharply after parturition. New nerve damage occurred in almost half of all women during pregnancy and lactation. Insidious silent neuritis was the most dangerous (Duncan ME, Pearson JM, Rees RJ 1981; TDR News 1997; Barrett.R 2005, Duncan.Elizabeth *in* Nunzi.E and Massone.C 2012). Vlassoff.C, Khot.S and Rao.S (1996) state that quite often affected women may not receive counselling about risks of pregnancy or the side effects of the drugs they are given. Thus, essentialization of gender role for a woman to bear a child and be a mother

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[13] This was exactly evident from the field.

also exacerbated their disease; without being informed about such risks when going for treatment.

Defined gender roles for men and women, also determine impacts and responses to leprosy at an individual and group level. Gender roles are expected for men as wage earners and women as care givers and home-keepers. In accordance with these socially expected roles, leprosy- affected females experienced more restrictions on their daily activities within the domestic sphere. (Try.L 2006). Varkevisser CM, Lever P, Alubo.O et al (2009) writes that men are more mobile than women, especially in rural areas where as women are tied with child care and other domestic duties within the confines of home although this may not always ensure quality of care. Study by Vlassoff and Bonilla (1994) in Colombia and India has indicated that in the case of women there has been a delay in treatment seeking until disease actually started to interfere with their daily activities because their tasks could not easily be deferred, which is again related to expectation from her to conform with her socially defined gender role. Writing in the context of impact of domestic labor on women's health, Doyal.L (1990) very appropriately writes that domestic work[14] (which is form of hidden uncounted form of labour) varies around the world but it universally involves low status, lack of economic power, inequalities in the allocation of household resources, and extensive social and emotional responsibilities. This holds very true in terms of analyzing gender dynamics which plays out in the case of women with leprosy specifically.

More often, men complained of experiencing stigma from family members. This is because women are socially conditioned to be submissive and accept imposed restrictions on them. Women is indoors engaged with domestic household work where as men are expected to go out and earn a living. This in itself brings in a stark contrast (Rao.S et al 1996). Looking at interaction between gender and patriarchal institution of the society is also crucial. In most cases, it is family members/husbands who decide the necessity to take woman of the house to health institution for treatment. Moreover, they

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[14] Even in the field, women who are affected do all household work, go to beg, come back and again get back to the work along with the care of their family. They also shared about times during their younger age when they had to leave one day's earning begging because of the difficulties at the time of menstruation. Contrary to this, for men situations are different. They too go out to beg but household chores is not their responsibility. They come back by evening, sit and chat in colony lawn and some do take liquor and then go to sleep. They do have a social circle at least within the colony and means of recreation.

are supposed to finish all household chores before leaving and long waiting duration at the health facility consumes considerable amount of their time. This conflicted with their domestic work and de-motivated them either to visit in the future or continue with the treatment any more (John AS, Rao PSS and Das.S 2010).

Samuel.P et al (2012) brought to fore gendered nature of migration on account of the disease. In the study, they found out that among all the migrants under study female migrants were more because of marriage migration. This is common in the society like ours where women marry and move into their husband's home. Usually children accompany their mothers while migrating. Rural-urban context along with other factors also brings in difference in reporting of cases. In urban areas, sex differences in registered cases were minimal, while in rural and tribal areas, significantly more males than females were registered (TDR News 1997).

All this is evident from the field situations as well which will be discussed in subsequent chapters. Gwatkin and Guillot (2000), as cited in Tolhurst et al[15] 2002, writes that gender is an often neglected but fundamental dimension of social aspects of infectious diseases which needs to be taken into account in order to effectively address the issue. Amongst the poorest 20 percent of the world's population, infectious diseases are responsible for six percent more deaths in women than men.

Thus, gender plays as one of the important social determinants of health. Gender differences and biases determine response of women especially, to the disease because of vulnerabilities created on account of physiological, socio-economic and cultural factors. Vlassoff.C and Moreno.GC (2002) very appropriately explain through their work that why gender is a key in understanding all dimensions of health including health care, health seeking behaviour and health status, and how a gender analysis can contribute to improved health policies and programming assisting in envisioning the goal of Health for All. Development of a gender equity approach needs to take into account existing gender inequalities, interaction between women's health and gender aspects of infectious diseases and thus vulnerabilities to diseases in order to effectively manage and control diseases leading to overall positive impact on health status.

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[15] They had given a framework to analyse gender inequities in infectious diseases (including Leprosy) in developing countries, which is given in Chapter 7.

1.5.4 SOCIAL DETERMINANTS OF LEPROSY

In principle, it is universally known that lower socio economic life conditions contribute to increased vulnerability of acquiring Leprosy infection and resultant consequences of varied nature and impact (Rao KV 1992, Ghimire M 2002, Withington SG et.al. 2003, Duarte MT, Ayres JA, Simonetti JP 2007, White.C 2008, Bonney J 2011). Some experts do believe in disease causation affected by social conditions like poor living conditions, close contact, poor diet and other such factors (Richards, 1977; Rubin, 1974 as cited in Covey.H 2001). Even during colonial times, there existed a British view about the disease which primarily afflicted the poor (Buckingham.J 2002). Physiological aspects like Genetic factors and one's immunological susceptibility is also responsible for contracting infections but it is certainly influenced by social determinants of health.

To understand impact of social conditions in leprosy, it is important to realise that there are both **intrinsic and extrinsic factors** in human populations which leads to leprosy and their combination determines the epidemiological pattern of the disease (disease spectrum) (Ehrenberg.J and Ault.KS, 2005).

Intrinsic determinants of leprosy are biological in nature (i.e. bacterial infection, immune response). Most of the intrinsic determinants can be manipulated only as a function of advances in medical research and technology (e.g., development of new vaccines, drugs and diagnostic tools). However access to services and technology for diagnosis and cure of leprosy has been difficult for certain segments of population which are poor clearly highlighting the issue of inequity in health services delivery, access and utilization by poor and disadvantaged.

Extrinsic determinants constitute external factors (outside the body) which impact affliction with the disease and its further progression or management. Conditions of poverty aggravate the conditions of living for leprosy patients. This not only ensures sustained transmission cycles but also promotes proliferation of the disease causing conditions. Conditions such as lack of access to health services, low literacy levels/ illiteracy, inadequate nutrition, poor hygiene increases, caste-class-gender further increases vulnerability to infection. This is especially true for poor pockets of under developed and developing nations. A study by Krishnan BK and Gokarn A (1992) among slum dwellers of Pune clearly states that the prevalence rate was highest in age group 31-40 years, females, Muslims, Widower/widow, skilled workers, illiterates and primary school educated and the lower socio-economic groups.

In India, caste also plays a significant social determinant of health. In Social epidemiological study done by Rao.KV (1992) in Chingleput District of Tamil Nadu, India clearly states that 43.7% of leprosy patients were harijans (from lower caste), a majority was illiterate with poor economic background. Sabiena.F et.al. (2011) through their study in Bangladesh showed that food shortage is an important poverty related indicator for the clinical manifestation of the disease. Another study conducted in Malawi showed that at an individual level living in a crowded household is a risk factor as is the lack of education (Ponnighas et.al. 1994). A remarkable community level study from Brazil shows that in an area where prevalence of endemic leprosy is high , higher levels of inequality was associated with higher levels of leprosy (Pontes.Kerr et.al. 2004). Much of these links may not be very directly visible also but they do play a crucial role in very covert ways.

Thus, Extrinsic and intrinsic determinants of leprosy synergize in a negative way when clustered together. A deficient diet leads to immune deficiencies and lack of nutrients in the body which leads to under-nutrition and to an increase in the susceptibility to disease. Although explanations in relation with exclusive genetic immunity are also available. This is illustrated by the fact that many of us carry the bacteria within but only some actually get infected. Lack of availability and access to health services results in the further deterioration of a person's health status. Biomedical cure of Leprosy through MDT can treat the disease but causes are certainly linked in socio economic conditions in which individuals and communities live.

1.5.5 MEDICAL PLURALISM AND PATTERN OF RESORT

In different parts of the world including South Asia, a range of multiple indigenous systems of medicine along with biomedicine have co-existed (Durkin 1984, Parker 1988, Leslie 1980, Nichter[16] 1989 as cited in Lambert 1996, Kirmayer 2004). Along these lines, Kirmayer (2004) identifies two models of healing. There is one general model of healing which includes both the physiological processes central to biomedical

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[16] It is important to mention here that work of foreign/other scholars, necessarily not directly linked with leprosy, has been referred. This is because essentially concepts used and explained were same which could be seen in parallel with medical pluralism and pattern of resort among people affected with leprosy. Moreover, in the context of leprosy nothing much substantial could be located.

paradigm and another model comprises of symbolic aspects of healing that have physiological, psychological and social effects. In many medically pluralistic societies (physician, spiritist/shaman, pharmacist, herbalist, registered medical practitioners etc) is widely accepted as a popular cultural norm involving multiple consultations for same ailment under different systems of medicine[17] and through different practitioners. It can be defined as co-existence of epistemologically diverse therapeutic traditions for health and illness (Lambert 2012).

Traditional forms of medicine have continued to be seen as bastion of cultural values and traditional healers have advantages in terms of availability and wider acceptability in the community. It is widely known that cultural beliefs and norms play a crucial role in shaping perceived disease causation, illness experiences, treatment seeking behaviour and defining of patient roles. There is distinct cultural patterning of 'diseases and their cures'. It should be noted that during episodes of ill health people make certain choices in search of a cure or better relief which is termed as 'pattern of resort'. These are likely to be flexible too. Health seeking can either be exclusive of one kind of treatment or successive or simultaneous (Kleinman 1980, Romanucci-Schwartz 1969; Garrison 1977; Woods 1977; Finkler 1981, 1985 *as cited in* Parker 1988). A tendency is also observed among people to refer to certain kind of healers or practitioners first and then switch to others which reflect hierarchy in pattern of resort[18] (Kleinman 1980, Lane and Millar 1987). In her work, Parker (1988) refers to the same stating that villagers 'shop for cure' in difficult cases and, if one is not immediately achieved, and then indeed multiple use patterns prevail. Lane and Millar (1987) report a hierarchical three tired system in treatment of eye diseases in a rural Egyptian village set up. People resorted to treatment within family, through traditional healers and by biomedical physicians. Of course there are pragmatic concerns and ideological perspectives which give a certain dispositioning to health seeking behaviour of people. Studies by Carstairs (1955) and Marriott (1965) investigated about resort to traditional systems of health on a priority basis by people residing in rural areas of North India. Similarly, Nichter's work (1978) in the South Kanara district of Karnataka, India, clearly states that there has been an

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[17] There has been some documentation of the same available in colonial times in the work of Jane Buckingham in her historical narrative. She brings in issue of slow and successive sidelining of traditional systems of medicine to cure leprosy by newer western system of medicine.

[18] Term was introduced by Romanucci-Ross in 1969 in her landmark publication which described sequences through which the peoples of the rapidly acculturating Admirality Islands in Mealnesia sought cures for serious illnesses that remained unresolved after initial therapy (often traditional) (Lane and Millar 1987; 152)

emergence of traditional referral network as a means whereby the multiple aspects of illness can be treated in the context of culturally perceived multiple causation.

Leslie (1992), as cited in Rao (2006), writes that in pluralistic system of medicine people have more autonomy in interpreting their illnesses and with wider choices available among different medical systems. Ethnographic work of Lambert (1996) among traditional folk healers in Rajasthan, clearly shows that the *medical domain (which includes all practices dealing with the treatment and prevention of ill health) is highly pluralistic and not clearly systematised.* Biomedicine is also highly popular chiefly in the form of injections and oral medications even in remote rural areas. These are administered either by unqualified practitioners or by trained doctors. There is a clear preference for private practitioners in contrast with government run health institutions. There are various reasons for the same which are logistical, social, economic and cultural in nature.

On a different note, medical pluralism shaped in distinct cultural contexts has been found even in countries like USA. A study among American women reflected about concurrent use of vitamins, herbs and homeopathic remedies along with prescription drugs and over the counter treatment drugs by over half of all respondents (53%). Personal beliefs were the common reasons for this kind of health seeking by women. One third people cited social influences as a reason. (Wade.C et al 2008). Work by Rutasha (2012) in Tanzania among people living with HIV/AIDS shows that 73% of respondents (total 228) first sought traditional medicine, with subsequent shift to bio medicine at a later stage. Researcher grouped determent factors into four group's: socio-demographics; cultural beliefs; institutional framework; and their experiences with health care systems. Kleinnman (1980) very appropriately wrote that clinical professionals are more disease oriented where as folk healers and indigenous practitioners are more illness oriented. But certainly disease and illness are both mediated in a cultural context.

Nichter (1978) did a study in rural Primary Health Centre zone in South India with a focus on illness specific patterns of resort in the selection of medical aid. It was found that in spite of popularity of allopathy many types of illnesses were first brought to indigenous practitioners. Villagers continued to utilize traditional and eclectic medical personnel. Study demonstrated that pattern of resort and existence of multiple therapy systems is related with cultural reasoning and social interaction as well as economic and educational variables. In relation with health seeking behaviour of populations it is important to recognize existence of pluralistic health arenas in developing countries and patterns of resort in using multiple therapies of systems.

One must realise that biomedical paradigm provides only symptomatic management of the disease but does not address causes, consequences and unique individual experiences of the disease among people affected with leprosy. People expect much beyond simple medical prescription of tablets, ointments, bandages and syrups. People's beliefs and perceptions about 'a particular system of medicine and practitioner' are strongly rooted in socio-cultural-economic considerations and which in turn draws people's attention towards traditional forms of medicine and healing.

Study by Rao (2006) among Asian Indian migrants to a metropolitan city in USA presents a similar kind of case. People were found to increasingly use complementary and alternative systems of medicine (CAM) with a simultaneous use of other available healing options. A clear hierarchy of resort was displayed in resorting to different health alternatives across practitioners. It emerged very clearly that people's decision to choose from different alternatives for treatment of an illness depends significantly upon people's perceived beliefs about severity of illness and effectiveness of treatment options while hierarchy of resort depended on kind of illness. Another study in USA by Kaptchuk and Eisenberg (2001) categorically states that during episodes of illness people have options of resorting to a variety of treatment systems and many do prefer to resort to pluralistic system of medicine.

Through her work in urban Nepal, Durkin (1984) suggested two basic patterns of resort in medically pluralistic settings across different cultures and geographical settings- illness specific and multiple therapeutic uses. While the former refers to classification of illness as responsive to a particular kind of treatment while the latter implies resorting to multiple health alternatives during an episode of illness.

At this juncture it is necessary to incorporate an understanding that 'pattern of resort' is not as simple as one's preference for western or traditional systems of medicine. Rather it is a more complex phenomenon determined by a range of situations and factors which are ideologically ingrained and driven with pragmatic concerns of people who are affected. A distinct nature of demand from patient's side (as described above Lambert

1996) has in fact compelled even informal practitioners (registered medical practitioners RMPs) to cater to these demands in spite of a limited or no knowledge about allopathy[19]. Kirmayer (2004) very appropriately captures this by writing about metaphorical transformations of quality of experience from illness to wellness and identity of the person from afflicted to healed, is central to any kind of healing practice. And this in turn calls for enactment of culturally salient metaphorical actions. It is very rightly stated that *'Illness experience is mapped onto a symbolic space created by the models and metaphors of the medical system' (reference not available).* And this mapping connotes specific meanings for the practitioner as well the person afflicted.

1.5.6 BEGGING AND LEPROSY

Almost every city or town or even rural areas have its own share of beggars, reasons for which are more systemic and structurally ingrained in a historical-socio-economic-cultural context. Begging is more of a survival strategy and a forced choice by those who are victims of certain situations (Cheng.C and Kumar.V 2012). It is important to recognize beggary as one of the social consequences of leprosy (Kumar.A and Anbalagan.M 1983; Vasundhara MK, Siddalingappa AS, Srinivasan BS 1983; Daniel JR, Maniar JK, Ganpati R 1984; Krishnamurty KV and Rao SP 1990). People affected with leprosy are the ones who are dehabilitated[20] from social processes and social relations because of loss of social value, loss of dignity, job or position leading to physical displacement (Kaur H and van Brackel W 2002a).

None of those who beg do it willingly and if given a chance are ready to quit from this humiliating, shameful and undignified work. They have just accepted it as a source of income over the years in the realm of no options available to them to fulfil their essential daily needs. But certainly deformities on account of leprosy and begging has destroyed their self image- their own conceptualization of dignity (Kaur H and van Brackel W 2002a,b). Over the years, indignity and humiliation have assimilated so deep down their hearts that they actually cease to look at themselves as 'human being' who is worthy and capable of living a respectful life with dignity. Often, they find themselves trapped in a situation where they can neither leave begging nor revert back to return to

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[19] In the field I had this opportunity to observe the same through an informal practitioner 'Bengali doctor' in adjacent slum. He caters to most of the health needs of people affected with leprosy and others from this colony.

[20] Term is used in the article by Kaur.H and Brakel.Van (2002a): Dehabilitation of leprosy-affected people: a study on leprosy affected beggars, Leprosy Review, Volume 73, pg 346-355

their homes or get engaged with some respectful way of earning their living because of the disease and attitudes of people.

It is imperative here to explore and understand what constitutes begging from the perspective of those who are engaged in it. This understanding enables to unravel how begging which is a marginalized occupation and also an identity category, is constructed by those who are involved in it (Staples.J in Staples.J *Ed* 2007). Harris.K (2011) writes about key role played by stigma in creation and maintenance of leprosy affected person's identity. Identity of a leper at an individual and group level fetches the category of deserving poor to those who beg (Caplan 1999 as cited in Staples.J 2005). Although begging is primarily an economic choice, it is given its social meaning through interaction. In the context of street level begging, leprosy becomes more than a social category. It is also a lived, bodily experience that can be manipulated as per the situations. Disguised self is revealed and made known as healthy for other social interactions in contrast with deformed and diseased self exposed at the time of begging (Staples.J 2003, 2007).

A clawed hand or a leonine facial feature that unequivocally speaks of leprosy invokes two kinds of responses from 'others'. One involved pity for this perceived group of people believed to be 'social outcastes' with spoiled bodies who could not make a living and another was of fear and disgust wherein people gave them prompt payment because this could remove them from the sight as soon as possible since 'leper' is seen as a possible source of physical and moral contagion (Staples.J 2005). People affected with leprosy often migrate to a different town or city, stay in small temporary settlements and earn a living mostly by begging and save some amount to send back home (Staples.J 2007). Migration to a different city also gives anonymity to their 'undignified and socially stigmatized way of earning'. Practice of begging certainly involves a context where all the social support systems have withered away and a kind relationship with 'others' who help in constituting categories of beggar and begging.

There are various aspects of begging by a leprosy affected person labelled as 'leprous beggar who does not want to work' by society at large. It is necessary to understand and explore the same. Staples.J (2007a, 2007b) informs about various analytical observations during his ethnographic fieldwork in a leprosy colony of Hyderabad. Incidents of violence or sexual harassment feature commonly in accounts of begging.

For economic and safety reasons, people prefer to beg either singly or in pairs because this fetches them not only more earning but also it is easier to escape when police comes. Children and most young adults (18-25 year olds) were excluded and discouraged from begging by their parents. Profile of people affected with leprosy who were engaged in act of begging, varied from the neediest and poorer ones to colony moneylenders for whom begging provided an additional means of capital. Sites of begging chosen also differ ranging from traffic signals, shops and streets to residential areas, religious places.

Having said that, a background is set in order to understand actual practice and experience of begging from an insider's perspective and how begging as a practice is embodied by those who are involved in it. Social construction of begging and leprosy both intersect as inter-related identities in the lives of those who are affected. Navon.L (1998) brings fore the point that beggars show of wretchedness and deformity creating a negative image is deliberately cultivated which actually upturns identities created in other contexts. By deploying bodily techniques such as stretching out clawed hand and displaying mutilated feet, deformities are wilfully exposed, accentuated or even invented in order to catch public pity. These deformities and image is otherwise kept hidden in other kinds of interactions. Paradoxically in the world of begging, 'physically inscribed diseased bodies' which are disenabling in one context actually become enabling 'marketable selves' in another context of begging (Staples.J 2005, Featherstone 1991 as cited in Staples.J 2007). Extent of 'deformities' becomes a hallmark of difference in income from begging[21]. Appadurai (1990;101) writes, as cited in Staples.J 2007, that '*begging is an exaggerated and intensified enactment of forms of dependence and types of interaction that are widely institutionalized in Indian society. Coercive subordination is used by them to catch attention from their benefactors'*. Practice of begging also deployed various embodied strategies in a given context where reconstitution of oneself as a 'leprous beggar' existed, disguised completely in a non-begging situation.

Looking at socio-economic aspects of people affected with leprosy siphoned off into beggary, is also important. A study by Rao PSS, Mozhi NM and Thomas MV (2000)

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[21] In relation with field situations this implies a person with mild forms of disability (Grade 1) is deemed to be unfit for begging while a person who is with severe deformities and wounds (Grade 2) is seen as a helpless wretched poor.

clearly states a majority of beggars from both the sexes were 50 year or older (upto 76 year in the total sample). Most of them were illiterate, migrants from rural areas and belonged to lower socio-economic backgrounds. Kaur H and Van Brackel W (2002b) through their work show that proportion of people with deformity were much higher amongst all whom they interviewed. Prior to contracting leprosy, all the men were engaged with farm work, manual labour and other such tasks. Findings match with the study of Rao PSS, Mozhi NM and Thomas MV (2002) as well where it was found high percentage of illiteracy and lower socio-economic background among all those who were engaged in begging.

1.5.7 SOCIAL NETWORK, SOCIAL SUPPORT AND LEPROSY

Social support within social networks and social integration has been reliably related with lower rates of mortality and morbidity among people (Schwarzer.R and Leppin.A 1991, Uchino.NB 2006). It is very essential to understand the role of social support derived from human relationships in determining etiology, progression, course and recovery from the disease. In the domain of health and illness, presence of social support can either improve overall experience or its absence can also lead to worsening of the condition. Psychosocial factors have a crucial role to play in disease etiology. Social support systems are created in a web of human relationships constituting social networks. It comprises of the people one communicates with, and the links which are developed within these relationships. There are two properties of social networks: *morphologic* which refers to links in the social network and *interactional* which is a communicated aspect (Kaplan.HB, Cassel.CJ and Gore.S 1977). Social support can again be in the form of instrumental, emotional, appraisal or informational (Kroenke.HC et al 2006). Social network is a web of social relationships surrounding an individual and within this provision of social support is one of important functions of social relationships. Hence, the term social network implies linkages between people that may or may not provide social support and may also serve other functions (Heaney.AC and Israel.AB *in* Glanz.K, Rimer.KB and Viswanath.K *Ed* 2008).

As stated before social ties within social networks play a beneficial role in the maintenance of psychological well-being. With embeddedness of individual social ties within the broader social structure thus emerges notion of social capital (Kawachi and Berkman 2001). Collective efficiency, psychological sense of community, neighborhood cohesion and community competence are four very important constructs that taps into slightly different but yet very overlapping aspects of social capital (Lochner.K, Kawachi.I and Kennedy.BP 1999).While social support refers to relations an individual develops with his/her social environment, social capital connotes influence of society upon individuals (Kritsotakis.G and Gamarnikow.E 2004). Ferlander (2007) recognizes the use of term social capital in recent times to describe certain resources and norms that arise from social networks. Social capital comprises of social networks, norms of reciprocity or social support and social trust. It clearly emerges through her work that social network is a core element which is further shaped by direction of ties and levels of formality, strength and diversity of ties. Kawachi et al 2004, as cited in Ferlander 2007, clearly state that by equating social capital with social networks and social support, one is only pouring old wine into new bottles. What is important here is to under the interrelationship between social networks, social support available within it and its impact on people's health (Berkman LH 1986).

There have been many studies which illustrate the link between social support systems of people and impact on health. For an illustration, Holmes, as cited in Kaplan.HB, Cassel.CJ and Gore.S (1977), noted that highest rates of tuberculosis in Seattle occurred among those people who were ethnically distinct unaccepted minorities in the neighborhood in which they lived or among those who were living singly. Disease incidence was frequent among those who were marginal for one or other reason with no social friends or intimate social group with which they could relate. Similarly a study done in America among women diagnosed with breast cancer found out that socially isolated woman had an elevated risk of mortality after a diagnosis with breast cancer mainly because of lack of access to beneficial care (Kroenke.HC et al 2006). Study among US men with coronary heart disease examining effects of social ties and change in social ties found out higher risk of mortality among men at lower level of social integration in comparison with one's who were more socially integrated (Eng.MP et al 2002).

Thus, upon minutely examining impact of social support and social networks upon health and illness of people, one finds a causal model as per which social support can have both a medicating effect on stress of illness and a direct impact on illness. It is imperative to understand that social integration, cognitive social support and behavioural social support are related to personality, stress, differential coping and pathogenic process (Schwarzer.R and Leppin.A 1991).

1.6 DIGNITY, STIGMA AND LEPROSY: A GLANCE THROUGH LITERATURE

Following sections in review of literature make an attempt to look at literature available in relation with basic conceptualization of dignity, various national and international declarations mentioning about dignity in general and leprosy in particular. Followed by this theoretical discussion we move on to next section which reviews literature available on stigma in relation with leprosy and health discourse at large. There are various theorizations regarding the same and an attempt has been made to shed light on them relevant to present study. Literature pertaining to stigma especially in the domain of biomedicine has been also reviewed as a spate section.

1.*6.1* CONCEPTUALIZATION OF DIGNITY AND LIVES OF PEOPLE AFFECTED WITH LEPROSY

"*Dignity is not something others give to you. It is something inherent in each of us. Recognizing the dignity inherent in every human being is the beginning of human rights.*"

- Bernard K. Punikai's, IDEA's president for advocacy 1997-2007 (IDEA Volume 13 No 2)

Deriving from contemporary debates in bioethics, there are apparently two main opposing conceptions of human dignity. The first is in the context of Kant's moral philosophy wherein dignity of the human person is inviolable-inalienable and links it to moral capacity separating it from the natural world. Kant conceptualized self-determination as foundation of human dignity, notion rooted in person's autonomy. While the second conception is more of a traditional one based on distinct position of the person in the world where human dignity is the value that rests in the person's essential mode of being, as an individual substance of rational and free nature. Human dignity is believed as a mystical property that is given in man but is also stripped from him in social interactions (Zúñiga.G 2003). Thus, to respect person's free choices is an implication of first view while respect to person's life and integrity is an implication of second view.

Hungarian philosopher Kolnai.A (1976; 253) identified three concrete features of Dignity:

> "*Firstly, the qualities of composure, calmness, restraint, reserve, and emotions or passions subdued and securely controlled without being negated or dissolved. Secondly, the qualities of distinctness, delimitation, and distance; of something that conveys the idea of being intangible, invulnerable, inaccessible to destructive or corruptive or subversive interference. Thirdly, Dignity also tends to connote the features of self-contained serenity, of a certain inward and toned-down but yet translucent and perceptible power of self-assertion*".

These features mentioned by Kolnai are largely, but not exclusively, of moral order but dignity cannot be identified simply with notion of morality.

Seifert.J (1997) has made an essential contribution in elucidating essential content and sources of human dignity. According to him, two diverging conceptions of human dignity imply two different sources of the same: one is 'ontological' and another is 'acquired'. And these two different conceptions signify two ways of conceptualizing personhood. Human dignity as an **ontological concept** is rooted in human nature as an individual rational substance and is equally shared by all human beings because of their very existence irrespective of their personal qualities or actions or behaviours. Kolnai.A (1976; 256) comments about dignity as an 'ontological value',

> "*Dignity is not perhaps simply a twilight zone between the region of the ethical and that of the aesthetic but also connotes a specific trait of 'ontological value*". Zúñiga.G (2003; 130) elaborates the same stating that "*dignity belongs to metaphysics—more specifically, to the ontology of personhood—and not to ethics.*"

This implied presence of dignity invokes a moral response, but yet ontologically dignity is not in itself, a moral quality and its examination does not fall in the province of ethics. **Acquired dignity** is grounded in awakened conscious life and actions (intentional or free) of human beings which actually leads to actualization of his/her potentialities and shaping of personality. Thus, in human life a person acquires another form of dignity in addition with ontological dignity, when he/she actualizes capacities according to values and goods, adding all together to a different level of person hood. Hence, the root of the person's essential dignity is in his/her unique mode of being as an individual substance of rational and free nature. And this mode of 'being' precedes actualization of any mental, physical properties and notions of morality (Taboada.P n.d).

It is also important to pay attention to a constructive interaction between dignity and belief in human rights within the domain of human relationships which is based on mutual respect for rights of people. Human dignity is principally ascriptive, inherent in all human beings independent of their distinctive virtues, mental levels and attitudes. It is inalienable much like rights of man but yet differences exist. Rights of man can only be unfulfilled. disregarded, violated or suppressed but 'human dignity' can actually be impaired, destroyed either permanently or temporarily. A vast scale of gradation also exits in the concept of human dignity in terms of 'more or less' based on certain traits or characteristics. Making distinctions between dignity as 'human dignity' and as 'a quality', is also necessary, human dignity is risked mainly by impact on us of powers alien to our will while lack of dignity as a quality is owed mainly to one's work: it cannot express itself or come to be except through our own agency. Notion of indignity wherein dignity is seen as a quality is associated with one's honour but this necessarily not lead to loss of human dignity (Kolnai.A 1976).

Human Dignity: A glance through international declarations and covenants

Here, the concern is with 'Human dignity' or 'Dignity of the human person' which has repeatedly gained mentioning in national and international declarations and conventions. Schatcher.O (1983) mentions about some of them in his work titled 'Human Dignity: as a normative concept'. Preamble of the charter of United Nations clearly mentions 'to reaffirm faith in fundamental human rights, in the dignity and worth of the human person, in the equal rights of men and women and of nations large and small'. Likewise Article 1 of the Universal Declaration of Human Rights (UDHR) highlights inherent dignity of all human beings 'All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood'. International conventions like International covenant on Civil and Political Rights, ICCPR (Article 10), the American Convention on Human rights (Article 5) also unfailingly affirm to 'respect for the inherent dignity of the human person'. Human dignity is not a standalone concept rather it is linked with other aspects of human life as well like Education. International Covenant on Economic, Social and Cultural Rights, ICESCR (Article 13) clearly reflects the same by stating 'education shall be directed to the full development of the human personality and the sense of its dignity'. State role and responsibility is also very crucial in ensuring human dignity. The Helsinki Accords (Principle VII) affirm that the participating states will promote the effective exercise of human rights and freedoms, 'all of which derive from the inherent dignity of the human person'.

Even recent inter-governmental instruments specifically dealing with biomedicine and adopted since the end of the 1990's by United Nations Educational, Scientific and Cultural organization (UNESCO) and the Council of Europe, also assign a central role to the notion of human dignity. There is also an appeal to human rights framework to reinforce the provisions. Thus, idea of human dignity has been at the core of major human rights instruments too which is reflected through various declarations, treaties and covenants (Andorno.R 2009).

Recounting the state responsibility, Amnesty International (2005; 6) clearly affirms that **State** must act to fulfil civil, political, economic, social and cultural rights of individuals and communities and refrain from violating these rights. It is a state responsibility to ensure no discrimination of any kind in the pursuit of realizing these rights. Government also had right to regulate behaviour of non-state actors to ensure that they respect human rights and inherent dignity of all human beings. And upholding of human dignity requires respect for fundamental and human rights of all people: there is no other higher priority than right to live life with a dignity. Harmonizing dignity of individuals with rights discourse report mentions

> *"The dignity of an individual cannot and should not be divided into two spheres – that of civil and political and that of economic, social and cultural. The individual must be able to enjoy freedom from want as well as freedom from fear. The ultimate goal of ensuring respect for the dignity of an individual cannot be achieved without that person's enjoying all of his or her rights".*

Notion of human dignity has been signified in three major ways through these international instruments – firstly, '*inherent...to all members of the human family*' (UDHR, Preamble); secondly, that all *human beings are free and equal in dignity and rights* (UDHR, Article 1); thirdly, that '*these rights derive from the inherent dignity of the human person*' (ICCPR and ICESCR, Preambles). These three ideas pave way for developing an understanding about the notion of human dignity and this notion is at the centre of human rights instruments too which prohibits practices such as torture, exploitation, oppression, discrimination etc (Andorno.R 2009; 6).

- Term inherently expressed in conjunction with human signifies that dignity is inseparable from the human condition. It is not a quality for few or an aesthetical value derived from certain specific personal features[22] but rather an unconditional worth that everyone has simply by virtue of human being and a worthy 'person'.
- Free and equality in rights implies if human dignity is same for all and the ground for human rights, then all human possess equal basic rights. Thus, discrimination, stigma, exclusion is in dire contradiction with human dignity.
- Rights derive from inherent dignity of human person implies basic rights are pre-existing values which are inherent in every human being, and cannot be legitimately taken away by any authority (Schatcher.O 1983)

Here it is important to understand that there is no precise definition of human dignity but yet it a very fundamental concept. Dignity is neither a synonym for 'respect' rather respect for people is a consequence of human dignity but not dignity in itself. Dignity provides a rationale to the respect of persons. Kantian conception was the first of its kind to conceptualize respect and dignity at the centre of his moral theory. It is also necessary to distinguish clearly between 'inherent dignity' and 'moral dignity'. While inherent dignity is inseparable from the human condition giving intrinsic importance to human life in ways that people are not denied from this intrinsic importance of their lives, moral dignity relates to behaviour of people and their ability to make good moral choices giving them honour (Andorno.R 2009).

International declarations and human dignity specifically in the context of Leprosy

People affected with leprosy are known to face intense stigma and devaluation of their very existence as a human being. Discrimination exists in every facet of life across the globe. Legal and social discrimination of people affected with leprosy is in fact gross violation of their human rights (Call for Change, The Leprosy Mission Trust TLM, year unknown). There are laws and regulations in certain countries which violate the notion of equal rights among people and restrict socio-economic opportunities for people who are affected. India has sixteen[23] such discriminatory laws some of them with colonial

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[22] Personal features vis-à-vis old- young, man-woman, healthy-diseased.

[23] Hindu Marriage Act 1955, Dissolution of Muslim marriage act 1939, Indian Divorce act 1869, Indian Christian marriage act 1872, Hindu special marriage act 1954, Hindu adoption and maintenance act 1956, Prevention of begging act 1959 (Maharashtra, Gujarat and Karnataka), Indian railways act 1989,

roots. Countries like UK (up till June 2012) , USA, Taiwan, Barbados, Hungary, Iraq, Namibia, the Philippines, Russia, Thailand, South Africa, the United Arab Emirates also keep a check on leprosy status of immigrants and visa can be denied based on this ground (Sasakawa Memorial Health Foundation n.d.). These are such laws and policies which serve to fan further the flames of prejudice, discrimination and devaluation of human dignity. This violation of rights of people affected with leprosy and their family members due to inequitable laws and social discrimination is a gross denial of their human rights and right to live life with dignity. In an Indian context, constitution of India (Article 14) affirms equal rights for all the people and under no circumstances any kind of deprivation from these rights can exist.

Seeing the seriousness of the problem and need for a timely action, United Nations human rights council (UNHRC) had passed a resolution (Resolution 8/13), endorsed by 59 countries, in June 2008 to end discrimination against people affected with leprosy and their family members. It was a reminder to each of endorsing governments to treat all individuals affected with leprosy and their family members with dignity, who are entitled to all human rights and fundamental freedoms. It also asked all governments to take effective measures to eliminate all forms of discrimination against people affected with leprosy and their family members. As a consequence of this, UNHRC's advisory committee submitted a draft set of principles and guidelines for elimination of discrimination against persons affected by leprosy and their family members in August 2010 (A/HRC/15/30). Subsequently in March 2011, this resolution was unanimously adopted by UN General Assembly (A/RES/G6/215). These principles categorically state that

> *"Persons affected by leprosy and their family members should be treated as people with dignity and are entitled, on an equal basis with others, to all the human rights and fundamental freedoms proclaimed in UDHR, as well as in other relevant international human rights instruments".*

This year on January 24, 2013 international bar association endorsed the eighth global appeal to end stigma and discrimination against people affected with leprosy and thus

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Rehabilitation council of Indian act 1992, Persons with disabilities act 1995, Motor vehicle act 1988, Life insurance corporation act (amended in 1987), Maharashtra state road transport corporation act 1980, Bombay municipal corporation act 1888, Industrial disputes act 1947.

bring back to focus 'importance of human dignity'. This global appeal is led by Nippon Foundation (Symposium Report by Paul Melly 25.02.2013).

1.6.2 STIGMA AND LIVES OF PEOPLE AFFECTED WITH LEPROSY

One is aware about ubiquitous use of the term 'stigma[24]' as a jargon very commonaly in leprosy discourse where the disease has been traditionally understood and projected as an epitome of stigmatisation. Use of the word 'stigma' has actually become a lazy shortcut for multiple social aspects of leprosy which prevents a deeper scrutiny (Staples.J 2011a). It is essential to unpack this term and look at it at the level of causes, forms and impact. It is necessary to transcend beyond the dominant construct of 'leprosy stigma' and look at it more holistically with a contextually ingrained understanding. There is a need to subjectively explore 'stigma' with a perspective based on people's experiences rather than simply objectifying with scales and instruments and using the terms as a shorthand for a whole gamete of intense negative social experiences manifested in very different ways and are of continuing kind over life time.

First we will review existing understanding about stigma as propounded by Erving Goffman during 1960's. Proposition by Goffman in relation with stigma was about an attribute/condition that is deeply discrediting but an emphasis was laid on the language of relationships involved. He brought in an interesting dimension of 'discredited' and 'discreditable'. While the former[25] refers to assumed differentness of stigmatized individual(s) which is known about already or is evident on the spot, the latter[26] refers to assumption by individual(s) that 'differentness' is neither known about by those present or immediately perceivable by them. This difference is important to be noted here because stigmatized individual(s) is likely to have experience with both the situations as in the case of people affected with leprosy. A distinct typology of stigma was also proposed: because of abominations of the body as distinct physical markers, blemishes of individual character and tribal stigma based on race, ethnicity, religion etc (Goffman.E 1963; 3-4).

Goffmanian understanding about stigma in sociological terms has been taken up to a next level by subsequent propositions inspired by other health related discourses.

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[24] Stigma, understood as a social process, involves two parties, the labeller and the labelled, and is, fundamentally, about otherness and the power to ascribe it (Harris.K 2011; 143).
[25] For example as in the case of people affected with leprosy.
[26] For example as in the case of Tuberculosis or HIV.

Goffman had propounded that stigma is related with a set of undesirable characteristics attached to an individual leading to a spoiled identity. Understanding which underlies here is that specific physical 'bodily markers' of individuals because of a disease/biomedical cause lead to manifestation of stigma in various forms. But it is a too simplistic way of associating stigma just with bodily conditions as in the case of leprosy and there is a need to transcend beyond the 'disease centric' focus of stigma (Staples.J 2011a). Lived experience of stigma can be best understood if stigma is looked at as an ongoing, dialectical process rooted in social relations and enacted within a specific cultural context. This calls for subsequent unpackaging of the term 'stigma' as a concept rather than conflating its causes, forms and effects (Harris.K 2011, Staples.J 2011a). No attribute/condition is inherently universally discrediting (White.C 2011). External factors shape stigma associated with leprosy in a specific socio-cultural-historical-medical-economic and political context (Staples.J 2011a, b, White.C 2011). This also bears impact on entire social experience of highly stigmatized diseases like leprosy.

There are two levels in the notions and experiences of stigma: one is at the level of individuals and another is at a larger level of commune. Both of them are essentially inter-linked and contribute in totality to experiences of stigma. Recognition of the same with consequent attention to differences and overlaps between the two are often missed out in a wider leprosy discourse. More popularly, in leprosy related work, a focus is laid more popularly on individual experiences of stigma (Harris.K 2011). Deriving from work in HIV-AIDS field it should be noted that at the level of community, stigma can act both as means of social control by 'normal dominant others' and contribute in creation of a shared identity and its representation at the level of those who experience stigma. This requires taking into account social models of stigma which demonstrates how stigma as a social process acts as a means to produce and perpetuate social power relations (Ogden J, Nyblade L 2005 *as cited in* Harris.K 2011). There is distinct language of social relationships in this social process where labeller ascribes the status of 'other' with a reaffirmation of his/her normalcy falling in line with normative construct (Joffe.H 1999 *as cited in* Harris.K 2011). It is essential to problematize this split between 'stigmatiser' and the 'stigmatised' in a process which is stigmatizing (Staples.J 2011a,b). Power and politics is constantly at play in viewing stigma as a social process in a state of constant change with inbuilt hierarchies which are aggravated further with structures of stratification and disparities. At times there are efforts of resistance too both at an individual and collective level which necessitates even more the need to recognize politics and collective shared experiences of stigma.

Kellersberger (1951), as cited in Weiss.M (2008), categorically writes that social stigma of leprosy was due to fear of the loathsome manifestations of the disease and beliefs according to which it was believed to be a moral/spiritual punishment. But, dwelling upon causes of stigma more minutely reveals that it is important to uncover and understand a certain set of prejudices or stigmatising attitudes or beliefs which are also associated with caste, class, gender, religion and/or ethnic inequalities in the society apart from the disease condition (leprosy) alone (White.C 2011, Staples.J 2011b). A mix of cultural meaning, avoidance of socially discomforting disfigurement and disability, exaggerated fear of danger and contagion are some of the rationales that give rise to stigma (Weiss.M 2008). There is a distinct context which breeds and perpetuates certain beliefs/prejudices manifested in behavioural and cognitive forms. Linguistic construction about the disease and popular usage in different languages and cultural contexts also impacts on whether or not or how stigma is constructed (White.C 2011).

Stigma is manifested and perpetuated in various forms with varying impacts upon individuals and communes which are stigmatised. Scambler.G (1998) had proposed 'hidden distress model' which can help in developing an understanding about forms of stigma. This model recognizes the differences between actual experiencing of discrimination or exclusion from its anticipation. Distinction between *enacted* and *felt* stigma can be further understood by understanding the differences between *anticipated* and *internalized* stigma. Internalization refers to acceptance of perceived exclusionary views of the society by a person with stigmatized condition leading further to self-stigmatization (Weiss.M 2008). In the context of leprosy, social problems experienced by people affected may also be attributable to self-stigma and low self-esteem. There are various ways through which prejudices and biases are enacted in practice by society at large. Natural history of the disease has much to do with self-stigmatisation among people affected and enacted stigma exhibited by the society at large. Diagnosis at a right time and access to treatment helps in preventing further complications of the disease and disfigurement which in fact becomes one the major reasons for fears and prejudices towards people affected with leprosy (White.C 2011). It is important to understand that problematization of the term 'superstition/ ignorance' is inadequate and it is often quoted as a reason for display of stigma by stigmatisers. Stigma is actually an outcome of a battle between ignorance and science in a milieu of countering traditions and societal norms (Staples.J 2011a).

While developing an understanding about stigma one should also pay attention to its impact and blurred use in the very mentioning of the concept. Experiences or perpetrated manifestation of stigma is situated either in a relatively more public or private context (Weiss.M 2008). Very importantly, stigma and discrimination should be recognized as two separate but linked issues where one often leads to another. Discrimination breeds labelling of individuals/groups with inattentiveness to other aspects of stigma (Deacon.H, Stephney I, Prosalendis S 2005). Stigma is a social process in which 'otherness' is constructed and hegemonically maintained and projected onto 'different others'. This kind of social paradox depending upon specific nature of the social context foregrounds the form and content of 'humiliation' among those stigmatized. Recognition, respect and dignity remain one of the vital needs of human beings in social relations which can be achieved in realm of elimination of any form of humiliation. In order to understand this better it is essential to look into a set of concepts like humiliation, shame, degradation, insult, indignity, misrecognition which constitute one logical class (Guru.G 2009; 2). There are well established links of stigma with social injustice, ostracism and victimhood within leprosy discourse (Harris.K 2011). White.C (2011;149) very appropriately writes *'the experience of stigma is a multilayered phenomenon that involves discrimination, exclusion, marginalisation, and lowered self-esteem; negative associations or beliefs about a particular status or condition within a particular culture play a role in how stigma is experienced, but stigma is 'multilayered' because any given stigmatising belief is usually linked to and compounded by other beliefs and other societal inequalities'*.

Goffman clearly brought out this relationship by propounding that stigma is harboured against a person with 'assumed differentness from the normative construct' and he/she is believed to be 'other' with a display of stigma through attitudes and actions. 'Other' individual(s) is seen as somebody who is not quite human and based on this assumption discrimination in varied ways is exercised. This certainly reduces their life chances and limits opportunities available. An ideology based on a construct of his/her inferiority and the danger posed, is continually propagated through one or another ways. Specific linguistic terms become everyday metaphors of degradation and one of the many ways of channelizing wider public imagery. Stigma is actually a special kind of relationship a whole range of beliefs about a particular 'attribute assumed to be different' anchored in certain stereotypes. At the level of affected individuals, perception of one of their own attributes as being a defiling thing to possess is constituted. Shame becomes of the central possibility with self-mortification and consequent dissociation from self over time (Goffman.E 1963; 5-7).

One should also notice the link between the disease (leprosy) and creation of a stigmatised identity which also becomes a shared identity and a means of collective representation and some means of social strength at a larger commune level. Staples.J (2005) terms this process as the paradox of 'disablement as enablement' in describing how people affected by leprosy embrace their stigmatised social identity in a bid for social power. One should notice that transformation of afflicted person's entire identity is something that is unique to leprosy. Person ceases to be viewed upon as a human being rather he/she is labelled as a 'leper' which transcends across all life domains (Silla.E as cited in Harris.K 2011). There is a claim of normalcy by dominant 'others' with a labelling of those with particular 'attributes'. In the case of a commune of 'people affected with leprosy' social relations are not as negative and stigma plays a key role in harbouring attitudes of empathy and development of group affinities. Distinctive bodily marking not only enables a sense of community but also allows mutually shared identities to build up (Staples.J 2011a). But here one should be aware that close focus on stigma alone limits the way lived experiences of those affected are understood by placing too much emphasis on a 'disease identity' at an expense of other interesting social identities (on account of caste, class, gender, religion, occupation etc) and factors in play. Leprosy is one of the many prisms though which lives of those affected by it are filtered (Staples.J 2011a,b) and one should be aware about the same while looking at people whose lives are affected with leprosy.

1.6.3 STIGMA AND BIOMEDICAL TREATMENT OF LEPROSY: UNDERSTADNING THE RELATIONSHIP

It is important to understand how health settings can also act as a site of origination and perpetuation of health-related stigma. White.C (2008; 25) coins a term 'Iatrogenic Stigma' in her work done in Brazil with outpatient leprosy affected people. She defined the term as *stigma that is produced through a patient's encounter with physicians or with biomedicine in general.* There are several aspects of an interaction between biomedicine and the people affected with leprosy which directly or indirectly generates or contributes to stigma, either felt or enacted. This stigma can be generated or experienced beginning from first encounter between health care workers/professionals and people affected who come for treatment, during the time of diagnosis and medication and various other such encounters when person affected seeks medical care. It can be manifested either directly or indirectly, verbally or non-verbally.

In fact, is not just cultural models of health, illness and body that determine and shape stigma towards a disease or health-related condition but also contextual factors such as caste, class, gender, religion, ethnicity/race, economic condition etc which influence to a great deal in shaping of stigmatizing attitudes and behaviours. Social roles, norms and values in a particular society, local constructions about health conditions and people affected, and other structural factors play a crucial role in shaping and manifesting stigma towards those who are affected. Culture in relation with health-related stigma has two dimensions: one is about the shared knowledge and behaviours of a population affected by illness and another is related with biomedical realm which comprises of a set of behaviours and beliefs which strongly influence on patient's experience of illness (White.C 2008). An interface existing between patient and health service system, strongly influences their own worldview about their bodies and illness. Medical systems and biomedicine is one of the potent sources of stigma generation and its manifestation except for few exceptional cases. It is important to understand here that iatrogenic stigma does not exist in vacuum and societal stigma does affect overall patient behaviour and experiences like treatment seeking, adherence to treatment, understanding developed about self and illness etc. Iatrogenic stigma is just one of the manifestations of stigma in a health setting.

Daspone Monodrug therapy was discovered as a treatment for Leprosy during 1940s. It was required to be continued by patients throughout their lives. In India, in an institutional hospital setting this treatment was being given to patients under observation. Biomedical justifications for the policy of patient internment were based on the lifelong requirement to continue with drugs to treat leprosy. An idea that patients should be monitored in order to prevent disabilities was prevalent. Moreover, 'active case detection[27] by identifying and notifying patients followed by isolation' was a

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[27] This kind of situation is true for other stigmatizing diseases as well like AIDS, TB etc.

component of national health programmes to control leprosy. This served to further perpetuate stigmatizing attitudes about leprosy that only intensified existing fear and prejudices among people against people who were affected with Leprosy (White.C 2008).

In 1985, MDT[28] drug regime was globally established by WHO. Treatment duration and medicines given depends on kind of Leprosy (MB or PB). Patients with successful completion of MDT are declared to be cured and non infectious but complications associated with leprosy are lifelong (neuritis, ulceration etc). Early identification of cases and treatment with MDT has been highly effective in reducing prevalence of Leprosy worldwide and prevention of disability. In spite of this, there are several aspects of MDT programme in itself that contributes to felt (self imposed) and enacted stigma. Selection of words while treating, the way diagnosis or disease information is conveyed to the patients, behaviour while dealing with the patients, treatment location etc could be few of many ways of displaying stigma (White.C 2008).

1.7 CHAPTERIZATION PLAN

Dissertation is divided into seven core chapters with bibliography and annexure towards an end.

Chapter 1 is review of existing literature which begins with a short introduction about leprosy as one the NTDs. Brief history of leprosy in colonial India is given in order to enable in understanding some of the present situations. This is followed by leprosy programme in post independent India. In order to understand magnitude of the problem, a brief picture of leprosy on a global and national scale is also presented with data derived from WHO and NLEP. Review of literature has been done keeping in consideration three objectives of the research concerned with life experiences, stigma and dignity in the lives of people affected with leprosy. Under life experiences, issues of migration, begging, gender, socio-cultural beliefs and perception have been reviewed deriving from literature specific to leprosy and general literature which is relevant to the study. Role of social determinants of health and social support networks in determining health status of people affected with leprosy has been also reviewed in brief. In relation with health experiences of people affected, a review of medical pluralism and pattern of resort in shaping of health and illness experiences of people has been also undertaken.

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[28] Novartis supplied MDT worldwide through WHO on outpatient basis.

This is followed by a review of literature focussed on conceptualization of dignity and reference of the same in various declarations. Final last section looks at stigma, leprosy and lives of people affected with leprosy across a different genre of literature in leprosy and in other related contexts like HIV, Hepatitis, and Epilepsy.

Chapter 2 is first part of methodology chapter which begins with assumptions, conceptualization, methodological framework, rationale and relevance of the research study. Research questions with broad and specific research objectives are also stated here. Research study design used in empirical work along with a brief note about data analysis plan has been also mentioned. A detailed note about entire data collection process has been written in order to best understand entire process of the fieldwork. Towards the end some operational definitions, study limitations and ethical considerations are documented.

Chapter 3 is second part of methodology which is more focussed on leprosy situation across seven districts of Delhi. Special emphasis has been laid on profiling present research areas along with research participant's details.

Chapter 4 marks the beginning of analysis which is spread across three chapters based on research objectives. Here, life experiences of people affected with leprosy have been thematically explored deriving from their narratives. Various themes like migration, gender, begging, social support network etc have been analytically explored.

Chapter 5 is specifically focussing on documenting and analytically looking at health experiences of people affected with leprosy. Narratives of participants have been thematically grouped into various themes like diagnosis of leprosy, medical pluralism and pattern of resort in treatment seeking, treatment experiences in Delhi and in native place, nature of relationship shared with health practitioners, interface between biomedicine and leprosy, narratives of illness etc.

Chapter 6 is focussed on understanding conceptualization of dignity and experiences of stigma impacting lives of people affected with leprosy in a variety of ways.

Chapter 7 documents major findings from this research study juxtaposing it with literature review. A discussion based on the same is synthesised followed by a brief conclusion.

CHAPTER 2: METHODOLOGY

This research study is aimed to study lived experiences of people affected with leprosy. For this purpose one leprosy colony in Delhi has been chosen (details of which are mentioned subsequently). Here it is important to mention that in the present work very consciously a decision has been made to use first person 'I'. Attempts were made to try writing using third person 'The researcher' but in the due course of writing it was realised very strongly that a natural spontaneous flow of words is missing in a coherent manner. In another trial, an attempt was made to try writing using first person 'I' and obstacles as mentioned above were overcome very soon.

2.1 ASSUMPTION OF THE RESEARCH STUDY

Study began with an assumption that in society at large, leprosy creates a dominant identity of '*a leper*' in the lives of those affected with the disease. Leprosy not only physically marks their bodies but also becomes a metaphor of illness for entire life. This not only leads to fear in the minds of people in the society but also exhibition of stigma in various forms towards those affected with the disease. There are multiple trajectories through which stigma manifests in the lives of people affected. Amidst life situations of this kind their conceptualization about human dignity is also impacted hugely.

Over time based on field work insights it was realised that leprosy is in fact one of the many intersecting identities in the lives of people affected. These identities are also shared at a community level which constitutes as one of the major binding force for them. It is necessary to realise that, leprosy does act as a trigger but there are certain pre-existing contexts and situations which give rise to distinct kind of situations in the lives of people affected with leprosy across different spheres. This experience is of continuing kind and does cut across caste, class, religion and gender.

Here, one must bear in mind that within the community/colony of people affected with leprosy there are very many binaries, variations and hierarchies. Leprosy colony is not a completely homogenous unit as it is popularly believed. Factoring in these differences is also necessary for a holistic account of life experiences of the residents affected with leprosy.

Present study deliberately attempts to look at lived experiences of both men and women. This aids in understanding and analysing entire experience of the disease which is not merely biological but also social with a gendered lens. Moreover men and women who are old and severely disabled because of the disease are worse affected. A single or deserted or widowed woman in such a case bears a double scourge of the disease. Her vulnerability is increased manifolds because of the disease which is highly stigmatized in the society.

2.2 CONCEPTUALIZATION OF RESEARCH

In relation with the society at large, Leprosy creates a dominant identity of a '*Leper/Kodi/Lachar/Bimar*' in the lives of people affected. But one must be aware that there are multiple intersecting identities (caste, class, religion, gender, occupation etc) existing in their lives which are beyond 'leprosy' but certainly associated with it as well. Constant humiliation, discrimination, social segregation and systemic exclusion have been an intricate part in the lives of people affected with leprosy. Very appearance of the patch on body leads to anticipation of stigma conjured up with leprosy and a distinct kind of treatment seeking behaviour takes shape. Denial, unawareness in certain cases and concealment delay the treatment process furthermore. Overtime as the disease progresses it leads to disability and disfigurement which creates more fear in the minds of people in the society towards people affected with leprosy. Life trajectory takes a distinct shape right from the time when patch appears. Stigma attached with leprosy needs to be deconstructed at three levels of causes-forms and impact. Stigma in the lives of people affected with leprosy is actually produced, mediated and perpetuated in a certain socio-economic-cultural-political-medical context. There is a very settled impact of stigma manifested in different forms in the lives of those affected which is very deeply internalized by them. Conceptualization of their human dignity takes a very distinct shape. There is a very slow and settled 'dehumaization' of self which completely ruptures their notion about self as a respectable human being. Life situations surrounded with multiple instances of indignity and experiences of stigma confronts their idea about self-their belief about existence as a human being. These situations are only routinized and compromised with over time.

In the present study, deliberately distinct life experiences of men and women are included. Gender is in fact one of an important axis of social inequality and discrimination among people affected with leprosy. Physiological, socio-economic and cultural factors play important roles in the response of men and women to *M.leprae* and impact of leprosy on their lives. There are certain gender roles, responsibilities defined for men and women in accordance with societal norms and cultural values, fulfilment of which is critical especially in the case of people affected with leprosy. Access to and utilization of services is also determined by nature of existing gender relations in the society. Having said that, women[29] are actually doubly jeopardized presenting a mix of factors amidst which she lives not only as a woman but also with an identity of a 'crippled leper' which completely juxtaposes her idea of self as a human. Moreover if she is widowed/deserted or single life situation is even worse. One must keep in mind that both men and women are negatively affected with leprosy and looking their unique life experiences in each one's perspective is crucial factoring in their frames of references.

In the present empirical work, an attempt has been made to theorize distinct life experiences of people affected with Leprosy (men and women) based on the concepts of 'stigma' and 'dignity'. Based on a range of theoretical propositions available and reviewed in literature review a synthesis of the same is presented in analysis and discussion chapters. It should be mentioned here that it was initially decided to use theoretical frameworks of Goffman and Kant for the present work. But as fieldwork proceeded and better insights were gained it was realized that restricting oneself to just alone these two theorizations was highly insufficient.

2.3 RATIONALE FOR THE STUDY

My research concerns often emanates from field realities and situations. Present research study is an outcome of the same. Journey in this field of leprosy has been very recent which originated during rural field work of M.Phil batch to Madhubani district in Bihar. During one of the visits in the villages I met an old person who was very severely disabled on account of leprosy. It was an opportunity for me first time ever where I interacted with a person who had leprosy. Interaction with him was imprinted onto my mind permanently and I wanted to explore and learn more. Soon after returning it was decided to take leprosy as a theme of my 1st year seminar paper. During the course of working on my seminar paper, my curiosity increased even more to know about the

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[29] Old women with leprosy or women with disability and leprosy or women with leprosy who are widowed or women with leprosy who are living with their husbands with/without leprosy.

field and lives of people affected with the disease. And this curiosity was eventually channelized in the form of my field engagement through empirical work of present dissertation. Reading, meetings with people working in the field and above all interactions with people affected with leprosy gave me more interest and an understanding about the field to mark a humble beginning of my work.

Through this study I also intend to engage with the concepts of stigma and dignity which play out very differently in the lives of those affected with Leprosy.

2.4 RELEVANCE OF THE STUDY

This study is important in the process of creating a more responsive health system catering to the health needs of people affected with leprosy in an integrated manner and an inclusive social structure in order to mainstream the people affected with leprosy. An inter-disciplinary understanding with a public health perspective has been rendered to the present work. Moreover, this understanding can be seen as one of the basis in looking at life experiences of people affected with other stigmatizing diseases like TB, HIV, Epilepsy etc. Major difference which remains is that leprosy cannot be hidden by people affected while in the case of other diseases one can still hide and avoid situations which stigmatizes them.

For a more concerted and sensitive intervention it is important not only to take into account various dichotomies, hierarchies and binaries which exist within the society and the colony but also at an individual level consideration of people's experiences of stigma and indignity over the years. This experience is also seen in relation with larger level community experience. Thus, for an envisaged empowerment of people affected with leprosy in real sense, it is important to recognize their everyday lived experiences in totality and incorporate this understanding at programmatic, planning and policy level decision making.

Although this is a micro level study but it does give very deeper understanding about a different life world of people affected with leprosy and this understanding is basic to any further step or planned intervention.

2.5 METHODOLOGICAL FRAMEWORK

This research study comprises of two major aspects: one is an attempt to do a brief literature review within the wider domain of 'life experiences of people affected with Leprosy' wherein I deal with two major concepts of stigma and dignity. Second aspect comprises of a primary fieldwork to explore and understand broad areas of research enquiry. Very consciously it was decided to use a qualitative research paradigm because the nature of enquiry is such which needs to unravel and understand subjective understandings of the research participants. Deshpande.M (2006; 22) very appropriately stated

> *"A qualitative research paradigm rests on the philosophical premise that one is striving to understand the meaning of the subject of study and not the frequency of occurrence of a phenomenon."*

Life history approach with a narrative inquiry is made into the lived experiences of people affected with Leprosy. Life histories of purposively selected research participants (male and female) have been documented based on certain variables from a leprosy colony of Delhi (South West district). Follow up interviews were conducted to fill in the gaps and enquire more in detail. An attempt has been made to capture their experiences as holistically as possible beginning from their past through their present and envisioned future. There have been a range of experiences which are social, economic, cultural, health related in nature. Stigma has been indeed crucial in having a major impact upon their lives with an influence on their conceptualization of dignity as well. Life history approach has actually enabled to look at various major events and other inter-related events in their life in a whole.

2.5.1 RESEARCH QUESTIONS

As a researcher I began this research study with following research questions:

- How leprosy as a disease shapes life experiences of people (men and women) affected by it?
- What is the experience of stigma in the lives of people affected with leprosy?
- How are notions of self-esteem and dignity constructed in the lives of people affected with leprosy?

2.5.2 BROAD OBJECTIVE

Present empirical study is envisioned to understand 'Lived experiences of people affected with leprosy' in one leprosy colony of Delhi with a rendering of theoretical understanding based on the concepts of stigma and dignity.

2.5.3 SPECIFIC OBJECTIVES

To understand

- Life experiences of people affected with leprosy (men and women) and the way this experience cuts across caste, class, gender and religion.
- Impact of stigma on the lives of people affected with leprosy and various ways through which it is manifested.
- Construction of dignity- an idea about self among people affected with leprosy.

2.6 RESEARCH STUDY DESIGN

Study is based on a qualitative research paradigm where narrative enquiry has been made into lives of people affected with leprosy. Quantitative data pertinent to research has been taken from reports, Government and Non-Government Organization (NGO) documents. Research setting is located in a leprosy Colony (Jeevan Deep Kushta Ashram) of South-West Delhi (RK Puram, Sector 1). This colony came into existence around mid 1980's (details of which are discussed in the subsequent chapter). All original residents had migrated from Northern Karnataka and now staying with 2nd-3rd generation who are their healthy dependents.

Purposive sampling has been employed to select eight participants[30]- four men and four women from the colony. To address stated objectives, an inclusion and exclusion criteria has been defined to select the participants. Detailed profiling of each of the participant is discussed in Chapter 3.

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[30] During my interactions I purposively selected twelve people (six men and six women) as my prospective research participants. But in the final analysis I could involve only eight participants. Reasons were: One of the interviews (male) was recorded in the field but after coming back when I played there was no audio recording in it. Since I was recording so I did not take any field notes also. For other two female participants I did not take any field notes but rather listened to them and memorized all the details. That particular day because of some reason I couldn't write field notes and very soon I forgot most of the details. With the 4th participant, I could complete only 50% of entire interview. While I was interviewing him he had to go immediately for some work and after this I did not get any chance to actually complete my interview with him.

Inclusion Criteria:

- Affected with Leprosy
- Able to communicate in Hindi or in some cases at least some level of understandable communication (this was the case with Women[31])
- Availability of people and willingness to communicate
- Resident of RK Puram Colony
- A mix of age group (old and middle age), grade 1 and grade 2 disability and marital status.

Exclusion Criteria:

- Healthy population in the colony
- People who were not present at the time of the study
- People who just could not communicate
- People who were not willing to participate
- People who were not the residents of this colony

2.7 DATA COLLECTION METHODS

Using life history approach, a narrative inquiry has been made into the lives of eight individuals affected with leprosy. Follow up in depth interviews were conducted to fill in the gaps and enquire more in detail. Utility of life history approach has been immense. *A life history could capture elements of change and struggles across life of various kinds* (Deshpande.M 2006; 19). *Primary Data* was collected through Narrative method, free flow personal interviews, non-participant observation and group discussions. These narratives including illness narratives often formed a part of main life histories. Few of the participants narrated very explicitly and differently about their illness. Key informant interviews (KII)[32] were conducted with colony heads, older people, people in the field etc. Insights from which have been incorporated wherever it was found to be relevant. Names of the participants have been coded in order to ensure confidentiality. Informed consent was taken from all the participants prior to audio recording.

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[31] Two of the women participants conversed only in Kannada. I took help from surrounding women and kids in order to converse with these two participants. But most of the men could communicate well in Hindi.

[32] Insights received from interaction with various field practitioners, policy makers, health professionals, lawyers etc have not directly formed a part of this research but these interactions helped immensely in building up an understanding about the field and connect issues in totality.

Checklist[33], field notes and audio recordings (which were transcribed later on) have been used as research Instruments/techniques in the field.

Secondary Data was collected from Journals, Books, Articles, Government, NGO and World Health Organinzation (WHO) reports & Documents. Survey data of the year 2010 of RK Puram leprosy colony has been also used which was received from Netherlands leprosy relief (NLR), India office. Reference work was done from the libraries of National Centre for Disease Control (NCDC), Tata Institute of Social Sciences (TISS, Mumbai), Jawaharlal Nehru University (JNU), Netherlands Leprosy Relief (NLR, Delhi) and The Leprosy Mission Trust India (TLM, Noida).

2.8 DATA ANALYSIS PLAN

Thematic analysis is used to explore and understand issues across all the participants. An attempt is made to look for variations and similarities in life histories of eight research participants. Narratives are content analysed in order to derive salient trends and patterns. Appropriate statements in the narratives are used under various themes and sub-themes. Since data set has been manually manageable so no qualitative research software has been used.

2.9 OPERATIONAL DEFINITIONS

Stigma: There are various definitions and range of conceptualizations available in relation with the concept of stigma. Here reference is made to one of the definitions given by Link.BG and Phelan.C.J (2001;363) in their work titled 'Conceptualizing Stigma'. They defined stigma as

> *"The co-occurrence of its components–labelling, stereotyping, separation, status loss, and discrimination–and further indicate that for stigmatization to occur, power must be exercised"*

As evident from review of literature stigma is a dialectical social process and thrives in a particular context. There is a process of stigmatization in which notion of 'otherness' is created by 'dominant others/stigmatisers'.

Discrimination: Stigma and discrimination should be recognized as two separate but linked issues where one often leads to another. Discrimination breeds labelling of

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[33] See Annexure.

individuals/groups with inattentiveness to other aspects of stigma (Deacon.H, Stephney I, Prosalendis S 2005).

Awofeso.N (2005; 101) in his work very appropriately wrote

> *"The term 'discrimination' embraces most, but not all, facets of the concept and impact of leprosy stigma. Goffman had defined stigma as an attribute that is deeply discrediting within a particular social interaction. Individuals with a stigmatized attribute fall short of generally accepted social expectations, and are therefore reduced to tainted, discounted individuals. The social hostility that results from such tainted perception of stigmatized individuals is commonly referred to as discrimination."*

Dignity: Writing about origin of the term dignity, Donnelly.J (2009;10) writes

"The English term derives from the (twelfth century) French dignité, from the Old French digneté. These in turn had their roots in the Latin dignus, worthy, from dignitas, which Lewis and Short define as "worth, worthiness, merit, desert."

As evident from review of literature, it is not easy to give one universal definition of human dignity. There are two sources of dignity: ontological and acquired. Whereas the former views dignity as respect to person's very existence and integrity, the latter refers to Kantian notion of dignity where dignity is seen as a moral quality. It calls for respect for person's free choices and right to self-determination. It lies in awakened conscious life and action(s) of individuals which can be either intentional or free. Related with ontological roots of dignity, is the notion of human dignity. It can be understood based on its certain features like it is inalienable, inviolable and fulfilment of which is necessary for the growth of human potentials to its fullest (Kolani.A 1976, Seifert.G 2003, Zuniga.G 2003). Dignity does bring in a sense of self-worth and self-respect among human beings.

Social Exclusion: Definition for social exclusion has been derived from the work of Sen.A (2000; 1) titled 'Social exclusion: Concept, application and scrutiny'. He writes

> *"The concept of social exclusion is seen as covering a remarkably wide range of social and economic problems. As Silver (1995), as cited in Sen.A (2000), notes, the list of "a few of the things the literature says people may be excluded from"*

> *must include the following: a livelihood; secure, permanent employment; earnings; property, credit, or land; housing; minimal or prevailing consumption levels; education, skills, and cultural capital; the welfare state; citizenship and legal equality; democratic participation; public goods; the nation or the dominant race; family and sociability; humanity, respect, fulfilment and understanding*".

Humiliation: Work of Gopal Guru (2009) scrutinizes the concept of Humiliation in great detail through his work 'Humiliation-Claims and Contexts'. Indeed there are various ways through which one can define humiliation. One of the definitions given in his work which is referred here is by Bhiku Parekh. It is given below.

> "*Humiliation involves disrespecting and demeaning others, damaging their self respect and causing them moral hurt and pain. Humiliation is an inwardly drive feeling which gets defined in terms of reception of the humiliating meaning of the tormentor assigns to the victim with an element of passivity.*" (Parekh.B in Guru.G 2009;6-9).

2.10 DATA COLLECTION PROCESS: ENCOUNTERING THE FIELD

Research design devised in the study addresses the stated objectives using a range of strategies and methods. Present study was conceived in three phases. **First phase**, involved selection of the leprosy colony in Delhi, **second phase** involved entry into the selected colony and rapport building with the residents and **final last phase** involved a more specific and in-depth interaction with the selected research participants. A systematic analysis of documentary sources and secondary materials forms an important component for providing the background and contextual understanding. It not only preceded the field work but has been an ongoing process which was further fine tuned based on insights from the field.

Phase 1: Selection of the Leprosy Colony in Delhi

I have been visiting leprosy colonies across Delhi since mid 2012 to November 2012[34]. My interactions with various people in the field gave me better understanding and important insights about various colonies situated across Delhi and national capital

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[34] Details of the same are given in the subsequent chapter.

region (NCR). It is important to mention here that very consciously; it was decided to take research participants from only one leprosy colony for M.Phil research rather than from an open community setting or more than one colony. Major reason for doing the same was time constraint in terms of finishing the field work. Field work was tried with an open community setting as well. This was done by meeting patients currently undergoing treatment for leprosy at All India Institute of Medical Sciences (AIIMS) and Guru Teg Bahadur Hospital (GTB) on fixed out patient days (OPD). But this did not seem to be best possible option mainly because of the time consumed. Inputs given by Dr SK Noordeen, ex-head of Global leprosy programme, WHO were helpful in initiating the same.

By October 2012, introductory mapping of the field was finished which included five leprosy colonies and one leprosy Complex (Tahirpur, Shahdara) in Delhi. So finally after an initial round of field visits focus was zeroed down to Jeevan Deep Kushta Ashram located in RK Puram Sector 1, Delhi. In November 2012, intensive field visits were started specifically in this colony. Choosing one single leprosy colony not only enabled an intensive qualitative study in a time bound manner but also much deeper insights about the lives of people affected with leprosy. There were three major reasons for selecting this leprosy colony in RK Puram:

- Since present study is qualitative in nature so it was required to spend more time with the participants stretched across multiple numbers of visits to the colony. RK Puram colony has been the closest among all and hence enabled me to visit it often and spend long durations of time (sometimes till dinner time).
- All the colonies visited have one or the other organization working in some or the other form. But in this colony none of the organizations are very active.
- Colony was quite criticized (in terms of non cooperative residents). I actually took this statement as a challenge and decided to explore beyond what was perceived. Moreover, this colony is located in one of the good areas of Delhi (RK Puram) so I actually wanted to see the contrast in the lives of residents of this colony who are not only a part of RK Puram locality but also of a leprosy colony.

Phase 2: Entry into the colony and rapport building with the residents and colony heads

I had visited this colony for a short time initially in October 2012 along with a staff member from one organization working with on issue of leprosy. There I was introduced to the colony secretary and dresser – **DS**[35]. Later, I revisited the colony again in November 2012 on my own and met **DS** again. This time he was more responsive and welcoming towards me. In no time I could sense the difference and the dynamics which probably exists between the organization and the colony members.

I also met other people in the colony (mainly elderly and middle age men) like **Er, KuS, Tho, IbS** etc. I kept visiting regularly thereafter. Initial visits were made just to get my presence counted as an independent individual. I was questioned and confronted by the residents in many ways but I over time as days passed it was all sorted out. Some people expressed various expectations from me like giving money, teaching their kids, getting medical treatment etc but my prior experience of working with communities enabled to put forth my position clearly in front of them. After an initial round of interaction with colony heads (**DS** who is a dresser, **Tho** who is Chota Pradhan and **IbS** who was Bada Pradhan that time and later **Ya** from 26 January 2013), very consciously it was decided to choose children and few adolescents from the colony as my entry point in the community. During various visits, I also did a social mapping [36]of the colony along with some children, adolescents and women from the colony. This was based aimed to identify households with people affected with leprosy, relationship networks, caste and religion wise distribution etc.

My first in-depth familiar interaction in the colony was with one colony woman who is a widow and stays with her three children in the colony. Her husband was affected with leprosy. She and her younger daughter suffered badly from Scabies. I took her to AIIMS and initiated her treatment along with full medication. This was initiated as an intervention but it turned out to be an important factor in strengthening my rapport with the colony. During the first few months of my field work (approximately November to December 2012), my role was merely not as a researcher but much beyond that. I did used to visit people's houses, attend their social functions, sit and chat with them, play with the children, watch television with them, intervene with certain most needy people

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[35] Names are codified throughout dissertation.

[36] See Annexure.

within my capacities or with cooperation from organization(s) etc. During the course of these two months I built not only a very strong rapport with the residents but also gained very crucial field insights which I kept recording on daily basis in my field notes. Gaining these insights would have been impossible if I would have accomplished my work in the colony merely as a researcher. Off late when I actually started interviewing people, I did share in brief my rationale for visiting the colony. People accepted it completely and expressed happiness too.

I did get support from Mr Brahm Dutt (Babuji) as well which really made my task easier in terms of getting credibility and an accountability when I met colony heads. I attended inauguration of Leprosy Union Federation office in Faridabad and I was asked to give an address to heads of various leprosy colonies across Delhi and Haryana. This proved to be quite important for me because representatives from the RK Puram colony who were present for the function did talk about my presence and addressal back in the colony. **Tho** mentioned to me the same when I visited the colony later on. Most importantly my visits to the colony were very regular and done in an accountable manner which made residents also very sure about my purpose.

Phase 3: Specific in- depth interaction with selected research participants and their healthy dependents

Slowly, people started recognizing me and interacting with me more openly. I carried myself in the field in the most spontaneous natural manner. This really helped me very well to mingle with people spontaneously and actually set most of my conversations into motion. Some started confiding in me by sharing their feelings, emotions, joys and jubilations, frustrations and sorrows. My foremost ethical responsibility in all these situations was to keep their trust intact and stick to the principle of confidentiality in any situation.

Gesture was also important apart from words and tone. I have been consciously very much aware of this every time I entered into the field. Research ethics have always been my guidelines before, during and after any conversation/interview. But there was always a scope for improvement each time I visited the colony. I did face a lot of field dilemmas- many of them got sorted out and answered on their own in the due course of time. I did a couple of free-flow interviews with Colony Heads, Bengali Dr, Temple priest etc. This was done mainly to get a sense about the field realities and co-relate them better. Every time I entered into the field my checklist for free-flow interviews kept getting modified and I did adapt it as per participants' in the field.

By early December 2012, I had finished four pilot interviews (two with men and two with women) in order to see emerging themes and how far these interviews meet my objectives. All these four interviews have been incorporated in final analysis.

My interaction with men affected with Leprosy was more as compared with women. It was not purposely done but entirely by chance. One major reason which played out here was – language. Most of the women in the colony spoke Kannada which was not familiar to me. I had started my fieldwork in November 2012 and a lot of colony residents had gone to their home town in Karnataka during that time for Moharram. Most came back by Mid December 2012. During this time very few women affected with leprosy were actually present in the colony and among them hardly anybody could converse in Hindi. Later when people came back, I could overcome this hurdle to an extent and very purposely selected rest of the women who communicated in Hindi or at least understood the language. But still choice available was very restricted. This did affect quality of interviews to an extent with few of the women participants.

2.11 STUDY LIMITATIONS

Every research study has certain limitations before, during and after the fieldwork. This study is also no exception. Some of the major limitations of this study are discussed below.

Fieldwork

Language: Unfamiliarity with Kannada language was one major constraint which not only affected my initial rapport building (during initial days) but also richness of data, number of questions asked, understanding of what my participants reply and probing. This played out to a major extent with two of my women participants. I was completely dependent on translation done by few community people and children. During the process of translation, if there was any manipulation or distortion I just could not make out. I had to accept what I was told by the translator. But yet, I tried my level best to probe by using various probes at different points in time with the same participant. At times translator also brought in his/her own interpretations and it was really difficult for me to separate the two- translator's interpretation and participants sharing.

Scope of the research study: This study is a part of M.Phil research which is a time bound task. It actually gives very less time to do fieldwork and then to write and submit it within a stipulated time frame. Keeping this in mind, only one leprosy colony was chosen and eight participants were finally selected to do an intensive study. Moreover, findings from this study cannot be universally generalized and in fact qualitative research in itself is representative of particular situations/settings. But certainly findings of this research study can be corroborated with other kind of studies in the domain of leprosy.

Informed consent of the prospective research participants: In the field a lot a people readily agreed to converse and communicate with me. But when subsequently I revealed my rationale and purpose of being there, at least three of them refused to be research participants and requested not to write what they shared. They said '*This is for your information but do not write*'. There was some amount of data loss on account of this.

Caste wise representation of participants: As it was envisaged in the beginning, I could not have a very uniform representation of participants across different caste groups. It could have been more broad with a large data set but diversity among participants involved in the present study is also good to begin with.

An ideal environment for interviews was not always available. At times, it was amidst people in the park adjacent to the colony or while conversing few others also used to join in. Disturbances were always there. Convenience of people was also a priority so at times compromises had to be made with interview environment.

Literature Search

One of the limitations while reviewing literature was a shortage of good quality research studies focussing exclusively on social science aspects of leprosy and its relation with social conditions especially in an Indian context. Most of the studies encountered were about clinical aspects associated with the disease or selected social dimensions of leprosy. Secondly, whatever amount of data I had access to I found very inadequate specifically in relation with India showing resurgence of disease.

2.12 ETHICAL CONSIDERATIONS

Some of the major ethical considerations in the present study have been listed below.

- Informed consent of the people

- Maintaining their confidentiality, anonymity and protecting them from any kind of perceived danger (non-malfeasance)
- Chance for participants to withdraw at any time (autonomy). Participation was entirely voluntary
- Sharing of the purpose of the research and outcome of the research (beneficence)
- Being sensitivity to issue and life realities of people
- Respect for their individuality and choices made
- Respect for justice and inclusiveness
- Duly acknowledging the data and literature used
- Ensuring independence of the research with declaration of no conflicts of interest

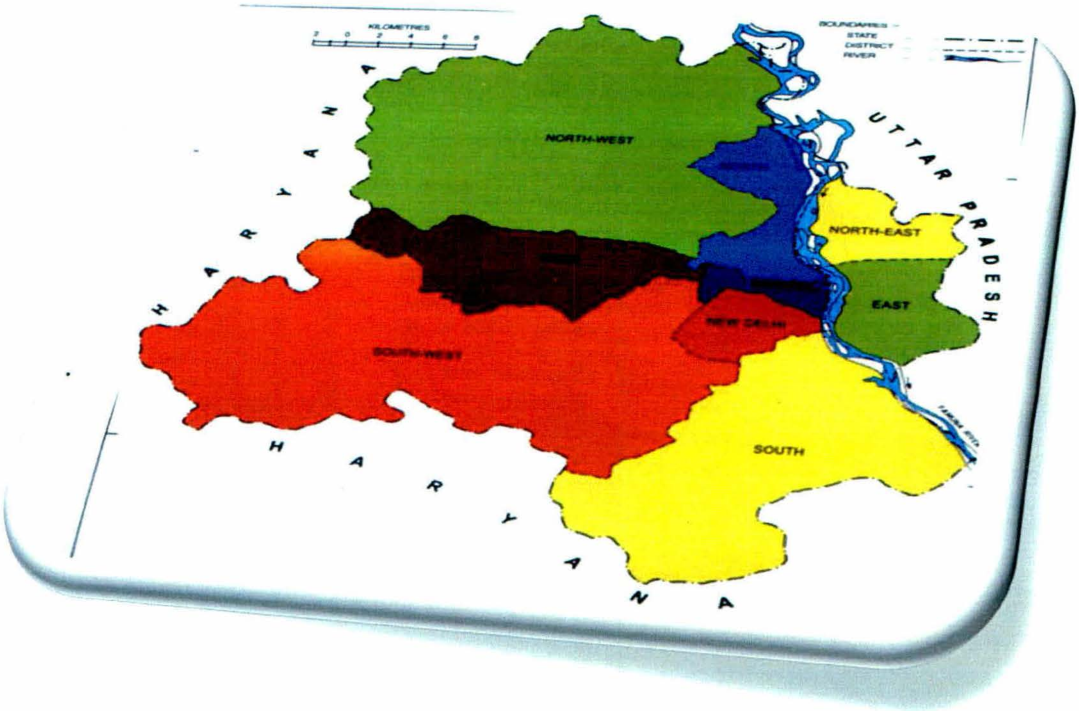
A very conscious attempt was made to keep these research ethics in consideration all the time.

CHAPTER 3: LEPROSY IN DELHI AND FIELD AREA PROFILE

3.1 INTRODUCTION: PREVALENCE OF LEPROSY IN DELHI

Delhi is divided into nine districts out of which only South, West, Northeast and Southwest districts have leprosy colonies (Figure 1). There are five leprosy colonies and one leprosy complex at Tahirpur, Shahadara (Northeast Delhi). This Leprosy complex has more than twenty leprosy colonies within including 'Village of Hope' which was constructed by Hope Foundation in mid 90's. Most of the residents in these colonies are migrants from different states of India which are endemic to leprosy like Orissa, West Bengal, Karnataka, Chhattisgarh, Tamil Nadu etc. There is a regional segregation in each of these colonies i.e. all or most of the residents are from the same state. For example, Nav Jyoti Kushta Ashram- Peeragarhi has all the residents from Tamil Nadu, Satya Jeevan Kushta Ashram- Lajpat Nagar has all its residents from Hubli and Bijapur Districts in Karnataka, Jeevan Deep Kushta Ashram-RK Puram has all its residents from Bellary and Gadag. This is possibly for the ease of common language of communication and same culture among the residents.

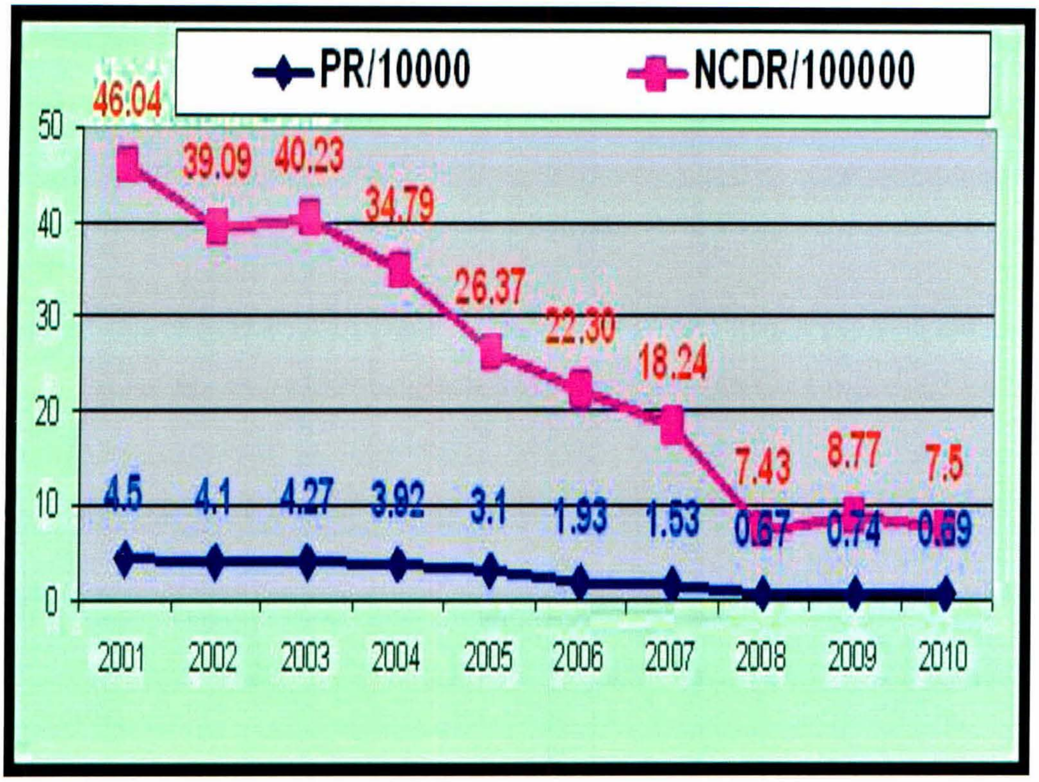
Figure 1 National capital territory (NCT) of Delhi with nine districts



Source: NLR India website Accessed on 20 April 2013

As per Delhi government data (National leprosy eradication programme NLEP Data, Delhi Government, June 2010) Delhi recorded a prevalence rate of 4.5/10,000 populations in March 2001 which has now come down to 0.69/10,000 population in March 2010. Annual new case detection rate (ANCDR) has reduced from 46/100,000 population to 7.5/100,000 population by the year 2010 (See Figure 2).

Figure 2 Prevalence of Leprosy in Delhi in last ten years (2001-2010)



Source: National leprosy eradication programme NLEP Data, June 2010 (last updated 18 Februrary 2012) Delhi Government

Interestingly Delhi Health Minister, AK Walia made an announcement (Times of India, IANS, 29 January 2013) on 24 January 2013 that leprosy has been eliminated from the national capital as a public health problem. This announcement has been made after a considerable drop in the prevalence rate of the disease. It has declined from a prevalence rate of 4.5/10,000 population to 0.8 at present. This is based on World Health Organization's (WHO) guidelines for declaring 'Leprosy eliminated as a public health problem'. Directorate of health services (DHS), Delhi Government has published data (National leprosy eradication programme NLEP Data, Delhi Government, June 2010) for nine districts of Delhi for the period April 2009- March 2010 which reiterates the declaration made by the health minister (See table 2)

Table 2 Data for nine districts of Delhi for the period April 2009- March 2010

Dist	Population	Total New Cases Detected	MB Among New Cases	Child	Females	Gr-II Disability	RFT/ Others	Cases on Rx Mar 2010	PR	NCDR
East	2028393	145	103	3	29	5	136	168	0.83	7.15
North East*	**2469336**	**248**	**180**	**26**	**67**	**36**	**252**	**237**	**0.96**	**10.04**
North	1091767	71	35	4	19	5	90	77	0.71	6.50
North West	3986577	236	119	5	65	7	264	163	0.41	5.92
West*	**2967665**	**151**	**98**	**6**	**35**	**8**	**199**	**114**	**0.38**	**5.09**
South West*	**2449429**	**118**	**67**	**6**	**18**	**6**	**156**	**132**	**0.54**	**4.82**
South*	**3161893**	**408**	**239**	**25**	**96**	**47**	**342**	**349**	**0.10**	**12.90**
New Delhi	240543	25	15	1	8	1	16	36	1.50	10.39
Central	901659	46	25	2	6	2	32	54	0.60	5.10
Delhi	19297262	1448	881	78	343	117	1487	1330	0.69	7.50

Source: DHS, Delhi government, 2010.

***Districts in bold have Leprosy colonies**

As revealed from this data, during the period 2009-10 new leprosy cases detected from Delhi were 1448 (MB – 881 & PB – 567). The patients treated during this period were 1487 (MB-917 & PB – 570). At the end of March 2010 there were 1330 cases (MB- 943 & PB -387) on record. Delhi is also detecting and treating leprosy cases coming from outside states. During the period 2009-10 new leprosy cases detected from outside states were 1699 (MB – 1203 & PB – 496). From outside the country (Nepal and Sri Lanka), there were 20 cases (PB-2 & MB-18). The patients released during this period were 1535 (MB-1061 & PB – 474). At the end of March 2010 there were additional 1739 cases (MB- 1393 & PB -346) on record (Delhi government NLEP Data 2010). Delhi government has also built two referral hospitals in each of the nine districts in order to confirm the diagnosis or for specialized care for reaction/disability care.

3.2 LEPROSY COLONIES IN DELHI

Details about each of the Leprosy colonies in Delhi are discussed below.

3.2.1 SOUTH DELHI DISTRICT

This district has only one leprosy colony (Satya Jivan Kushta Ashram) located in Srinivaspuri, Lajpat nagar. As per Netherlands Leprosy Relief (NLR) survey data[37] (2010), there are 166 residents in this colony out of which 46 are affected with Leprosy. 36 people have multiple disabilities, seven have disability of hand and three have in feet.

Epidemiological picture of the District

Both prevalence rate and ANCDR have shown fluctuation since 2004-05. South district has not achieved the elimination status, yet. The high proportion of Multibacillary (MB) cases (61.9%) and Grade 2 disabilities (17.2%) amongst new cases suggest that the cases are reporting late for treatment. There are low proportion of females (18.9%) amongst new cases in the light of high MB and Grade 2 proportion suggests that the cases from outside the state are usually adult males and make up the majority of cases that are registered in the district. This is further supported by the fact that the proportion of children amongst new cases is small and is stationary since past 5 years (NLR India, 2010;a).

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[37] Government data could not be obtained in spite of trying.

In this district, treatment completion rate (TCR) for the cohort year 2006-07 for MB cases has been 48.84% (Male: 50.68% and Female: 38.46%). For Paucibacilliary PB cases for the cohort year 2007-08, TCR has been 72.22% (Male: 72.34% and Female: 72%) (Singh.DB, 2009).

3.2.2 WEST DELHI DISTRICT

This district has three leprosy colonies, Lok Mata Kushta Ashram in Patel Nagar, Nav Jyoti leprosy association in Peeragarhi and Jagat Mata Kushta Ashram in Tilak Nagar. As per NLR survey done in 2008, Lok Mata Kusht Ashram in Sadipur, Patel Nagar has 75 residents in the colony, out of which 35 are affected with Leprosy. 12 have a disability of eye, 34 have disability of hand and 30 have of feet. Nav Jyoti leprosy association, Peeragarhi has 20 residents out of which 15 are affected with leprosy. Three are affected with disability of eye and all 15 have disability of feet and hand. Jagat Mata Kushta Ashram, Tilak Nagar has 93 residents out of which 27 are affected with leprosy. All 27 have disability of hand, 23 have of feet and four have disability of eye.

Epidemiological Picture of the District

There has been a steady decline since 2004-05 in prevalence rate and ANCDR in the district but yet elimination status has not been achieved. The high proportion of MB cases (77.8%) and Grade 2 disabilities (9.47%) amongst new cases suggests that the cases are reporting late for treatment. There are low proportion of females (20.8%) and children (4.92%) amongst all the cases. Proportion among children is almost stationary for past five years (NLR India website,2010;b).

Treatment completion rate (TCR) for this district for the cohort year 2005-06 for MB cases was 29.41% and 50% for PB cases in the cohort year 2006-07. TCR in the cohort year 2006-07 for MB cases was 69.1% (Male: 65% and Female: 80%). Similarly for PB cases in the cohort year, TCR was 86.44% (Male: 88.24% and Female: 84%) (Singh.DB, 2009).

3.2.3 SOUTH WEST DELHI DISTRICT

South west district of Delhi has only one leprosy colony 'Jeevan Deep Kusht Ashram' in Sector 1, RK Puram. NLR did a baseline survey[38] in 2010 according to which there

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[38] This data was obtained from NLR in tabulated form in their reporting format.

are 183 residents in the colony out of which 53 are affected with Leprosy. 38 people have been recorded to have multiple disabilities (for details refer to Section 3.3.3).

Epidemiological picture of the district

In this district, prevalence rate and ANCDR have declined steadily since 2004-05 but like previous districts here also elimination status has not been achieved. The high proportion of MB cases (55.3%) and Grade 2 disabilities (11.3%) amongst new cases suggests that the cases are reporting late for treatment. The low proportion of Females (24.2%) amongst new cases in light of the high MB and Gr 2 proportion suggests that the adult males from outside the cases make up the majority of cases registered in the district. This is further supported by the fact that the proportion of children amongst new cases is small (4.6%) and is stationary since past six years (NLR India, 2010;c).

Treatment completion rate (TCR) in this district for the cohort year 2006-07 for MB cases was 46.30% (Male: 43.18% and Female: 60%). For PB cases in the cohort year 2007-08, TCR was 64.86% (Male: 62.82% and Female: 69.70%). Among all the three districts (West, South and South West), South West District has lowest treatment completion rate both for MB and PB cases during the cohort year 2006-07 and 2007-08 respectively (Singh.DB 2009).

3.2.4 TAHIRPUR LEPROSY COMPLEX IN NORTH EAST DELHI

Established half a century ago, Tahirpur Complex is one of the largest colonies of people affected with Leprosy in Asia which is spanned in 74 acre of land (Utkarsh.A, 13 January 2011). These people have been rehabilitated decades back and stay here along with their healthy dependents. Tahirpur is now a witness to third generation of original inhabitants of this complex. A lot of them are migrants to Delhi from the states which are endemic to Leprosy like Tamil Nadu, Karnataka, Orissa, West Bengal, Chattisgarh, some districts of UP etc. Reasons are many which are discussed in analysis Chapter 4. Many of the residents stay here along with their families and go about regular life activities. Residents are from diverse backgrounds and cultures, caste, class and religion with one commonality - they all are affected with leprosy. Undoubtedly it is a ghettoised group of people who share a same identity because of the disease and are socially segregated but yet form a small mini world of their own. Nature and patterns of relationships, group interactions and hierarchies which exist here are as similar as it exists in any other society.

One noteworthy aspect of this complex is 'Village of Hope' which houses 800 families in 792 houses (Hope foundation, n.d). These 800 families are former residents of the Municipal Corporation of Delhi (MCD) leprosy complex. Before the construction of village of hope, they all used to live in mud and straw houses with no basic essential services. There was open drainage system and filth in entire area which only aggravated their existing health condition(s). Social stigma attached with the disease and poverty left them with no option except to live and suffer in this locality. Begging was the sole means of making their ends meet. Seeing this apathy of people and their life conditions in Tahirpur in 1993, HOPE foundation collaborated with the Department of Social Welfare (Government of NCT-Delhi) to establish the Village of HOPE initially with 444 houses and later by May 2003, 792 houses were built. These 800 families have now proper *pukka* houses with all basic essential facilities like free electricity, water supply, a proper sewage system etc. HOPE Foundation has its own dispensary and vocational turning centre. There is one government primary school in the locality where children of residents study.

Many Non-Government Organinzations (NGO), International NGOs, Community Based Organizations (CBOs) and Government Departments like Social welfare department are active in this complex.

3.3 STUDY AREA PROFILE: JEEVAN DEEP KUSHTA ASHRAM, RK PURAM

3.3.1 INTRODUCTION

Jeevan Deep Kushta Ashram is one of the leprosy colonies in Delhi located in RK Puram, Sector 1 area of South West district. Location wise this colony has one of the best locations among all with necessary basic facilities. One of the main reasons for this is its location in South West Delhi which is one of an affluent area in Delhi. This colony also receives high amount of donations from people in and around the locality. Very often one or two time meal is also sponsored by people. It is located just next to the main road and is a part of larger RK Puram Ambedkar slum with a distinct recognition as Kushta Ashram.

It comprises of 63 households and 180 residents comprising of healthy dependents and people affected with leprosy. There are two Christian houses and 7 Muslim houses in the colony. Rest all are Hindu. People are from diverse caste groups like Lingayat, SC, OBC, ST. Economically almost all are very weak and poor. None of them have ration or below poverty line (BPL) card. Most of them earn their living by begging, few get pension and seven of them work with MCD as sweepers on temporary basis. Each house has one or more person(s) affected with the disease. Some houses are occupied by healthy dependents of people affected with leprosy. Two houses are empty presently and come under Panchayat (colony administrative body) of the colony. All the residents are migrants from North Karnataka mainly from Bellary, Bagalkot, Hubli, Gadag and Yadgir (See Figure 3) districts. If any new person affected with leprosy wishes to take house in the colony, he/she has to pay stipulated amount of the house (approximately Rs 65,000) to colony Panchayat and take permission before occupying the house. Residents who pay the money are part of the Panchayat and are eligible to avail all the benefits as residents of the colony like share in material which comes as a result of donation or charity activities etc.

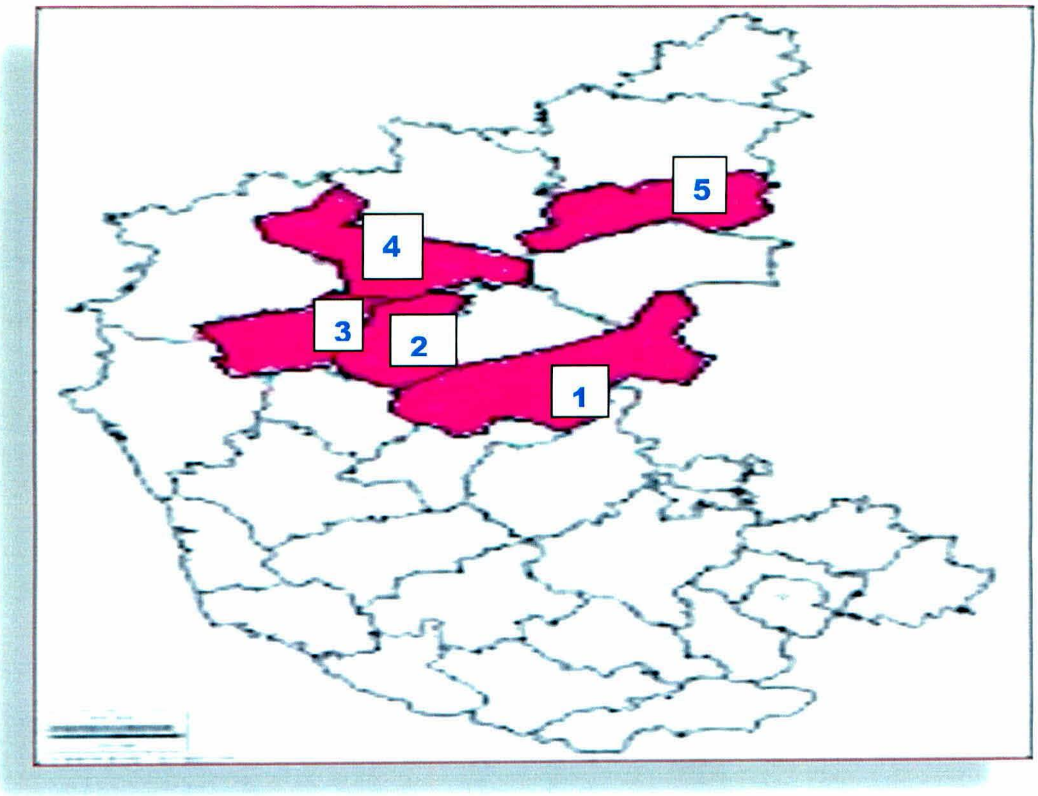
Closest government health facilities are Motibagh dispensary, AIIMS and Safdurjung hospital. Close to the colony there is one charitable Asha Polyclinic run by Maitryee Mission. They also have a dispensary in the colony itself. As per the residents it is closed most of the times. There are plenty of private clinics in the surrounding area. One Bengali Doctor in Ambedkar slum caters to most of the health needs of the residents. If situations are beyond his control he refers them outside.

There is one protestant group church and one Sai Baba temple in the colony. Colony has two Kirana shops within run by two residents. There are four washrooms at two corners of the colony- four each for men and women. There is one common water tank and two common taps which cater to water needs of not only this colony but also some residents from Ambedkar slum as well. Anganwadi is in adjacent slum but none of the colony kids go there. Children of the residents study either in Najafgarh (run by Missionary), Haridwar, Back home in Karnataka- Bellary (run by a Missionary) or in close by government school.

There are two organizations which are present in this colony. One is Maitryee Mission and another one is NLR. They have initiated one self-care group in the colony since 2010 and distribute stationary among school going children of people affected with Leprosy. Advocate Brahm Dutt is the main concerned person in relation with all the legal matters of Leprosy colonies in Delhi including this one.

For administrative functioning this colony like others has Bada Pradhan, Chota Pradhan and a Secretary. They are elected each year during colony meeting where mainly men are present. With a consensus, an older and experienced man is selected as Bada Pradhan. He can continue or discontinue based on colony residents' opinion about his work. State Leprosy Office (SLO) has appointed one dresser in each of the colonies including this one whose duty is to do dressing and cleaning of wounds (on alternate days) of people affected with leprosy. Supply for bandages and medicines are from SLO's office on a monthly basis. Colony has a system of monthly meeting in the fourth week of every month and committee meeting in the first week of every month. This is meant to discuss major colony issues. Residents based on their financial capacity put 'committee' with Panchayat which is basically depositing a fixed amount of money every month which can be withdrawn in times of need.

Figure 3 Districts in North Karnataka from where people have migrated to this colony



1:Bellary 2: Gadag 3: Hubli 4: Bagalkot 5: Yadgir

3.3.2 ORIGINS OF THE COLONY AS REVEALED BY THE RESIDENTS

I spoke to old and initial occupants of the colony about origins of this Ashram. All of them related its origins to the times when Rajiv Gandhi government came into power (October 1984 to December 1989). Initially this colony was a piece of land where people settled down illegally in *kaccha* houses made up of straw and polythene. Some of them stayed under an open sky. At night and during rains they used to go and sleep in the parking space of adjacent government offices. This piece of land was not only a home for people affected with Leprosy who had migrated from their native states but also gave shelter to many other homeless and needy people. It was all a mixed population.

Slowly with intense advocacy efforts overtime under the leadership of Advocate Brahm Dutt and Laxshmi Madam (people often named her who used to stay in RK Puram. She is no more now), permission was taken from the government for this land. Inspired and motivated by Babuji (Adv Brahm Dutt) and Laxshmi Madam, a delegation of 10-15 people met the present government. Finally, written papers of the land with authorized signatures were handed over to these people. After gaining land entitlement initially temporary make shift houses were built on this land. Slowly with the help and donation by one Sardar Baba (One Sardarji addressed as Sardar Baba by colony residents) from Moti Bagh, some pukka houses were constructed. More donation and political support poured in with time. All the houses were made *pukka* with proper road and drainage system. Government provided free electricity and water supply to this colony and now all the leprosy colonies in Delhi have this facility.

One of the colony woman who has been staying here for past 30 years along with her third generation shared

> '*Sabse pehle Delhi mein issi area mein aa gaye hate. Tab ghar nahin hata. Yeh Daftar hain na wahi gujar basar kara karib 6-7 saal. Abhi yeh sara aisa khula badiya banaya hai tab aisa kuch bhi nahin hata. Koi garib log koi kuch rehne ke liye dete. Aisa khula hata (pointing towards Park attached with the colony) barish gire toh office niche so jate. Khule dino mein aisa Park mein sote. Udhar hi raha 6-7 saal. Bimari kya tumhara (pointing towards me) jaisa accha log bhi tha. Yeh karib 1980 ka baat hai'*. (For the first time when we came to Delhi, it was this area and we had no house. We all used to stay underneath that office for 6-7 years. All this that you see now, nothing was there at that time. It was all open space and

> we used to run and sleep underneath those building when it used to rain. Not only people affected with Leprosy but also other healthy people used to stay in this park. This was somewhere in 1980.)

She continued adding

> *'Lakshmi Madam aur Brahmdutt Babuji hate. Humko dono milke aisa piche pada- tum kaise aa gaya-aisa kaise reh raha ho. Tab Rajiv Gandhi hata. 10-15 lachar lachar log aur Babuji, Lakshmi Madam milkar sarkar ko mila. Woh kya kare aisa saare ko dekh kuch meherbani aya hoga- Kagaz par sayahi (Signature) bana diye. Bola ki yeh jagah ab tumhara. Tum Jhuggi daal reh sakta ho. Koi bhi nahin uthaega. Ekdum phir kya Babuji aur Madam hamare picche padke thoda thoda ghar daal diye. Bahut garib hate log- abhi toh bhagwan sab thik thak kar diya hai. Moti Bagh mein ek Sardarji hata woh thoda thoda Pukka Ghar banwa diya. Bijli Pani bhi Sarkar dhire dhire de diya. Sarkar office samne ja khub dharna diya tha. Sab ho gaya dhire dhire'.* (Lakshmi Madam and Brahmdutt Babuji were the key forces behind our struggle. During Rajiv Gandhi's time, 10-15 of our disabled leprosy affected people went and met him along with Madam and Babuji. Rajiv Gandhi gave written permission on paper to construct houses on this piece of land. People were very poor that time, now situations are still far better. There used to be one *Sardar Baba* in Moti Bagh who came forward to build *pukka* houses for us. Slowly electricity and water connection was also granted by the government. Everything came on track one by one.)

It is imperative to mention here that all factual details provided above and description about colony origins has been shared overtime during various instances. All this information has been collated and presented in an orderly form in order to decipher about origins of the colony.

3.3.3 COLONY PROFILE

Data[39] for this colony was obtained from NLR which is a part of baseline survey done by the organization in 2010. I did try obtaining the same from SLO office but could not manage. Hence I had to rely on this data obtained from the organization and house listing obtained from the colony dresser. I did a social mapping (See Annexure) of the

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[39] There is no socially disaggregated data available for this colony.

colony for an ease of identifying households based on certain variables like caste, religion, households with presence of people affected with leprosy etc.

This colony has 65 households and total 183 residents, out of which 53 (Male: 34 and Female: 19) are affected with leprosy. There are 27 families in this colony where one or more people are affected with leprosy. Among these 53 people, 22 (Male: 14 and Female: 08) people are in the productive years of their life (16-45 years). 27 people (Male: 17 and Female: 10) are in 46-60 years age group and four people (Male: 03 and Female: 01) are more than 61 years of age. In this colony nobody below 15 years is affected with leprosy.

Out of 183 people, 69% are illiterate. This constitutes a large number of people from the colony who have not even attained basic education to at least read and write. 19.1% have primary level of education, 9.8% have passed 10th standard, 1.6% have passed 12th standard and only one person has finished graduation. Table 3 gives a detailed data about literacy status of this colony.

Table 3 Literacy status of the residents of Jeevan Deep Kushta Ashram

Education Level	Male Adult	Male Children	Female Adult	Female Children	Total
Illiterate	28	41	40	17	126
Primary	10	11	03	11	35
10th Grade	09	03	01	05	18
12th Grade	02	Nil	01	Nil	03
Graduation	01	Nil	Nil	Nil	01
Total	50	55	45	33	183

Source: NLR Baseline survey data 2010 (Unpublished: Obtained from the organization)

Among people affected with Leprosy, 14 adults suffer from Grade 1 disability (Male: 06 and Female: 08) and 39 adults suffer from Grade 2 disability (Male: 28 and Female: 11). Table 4 gives a detailed account of the nature of disability among people affected with Leprosy in this colony.

Table 4 Disability status of people affected with leprosy in R.K Puram Leprosy Colony

S.No.	Particulars	Male Ad.	Female Ad.	Total
a)	With foot Ulcers	20	05	25
b)	With anaesthesia in hands	26	12	38
c)	With anaesthesia in feet	28	16	44
d)	With Lagophthalmos eye	03	03	06
e)	With Corneal anaesthesia	03	03	06
f)	With deformed hands	27	11	38
g)	With deformed feet	25	09	34
h)	With multiple disabilities	26	12	38

Source: NLR Baseline survey data 2010 (Unpublished: Obtained from the organization)

Main source of income for people affected with Leprosy residing in this colony is from begging. 88.6% of people (Male: 29 and Female: 18) affected with leprosy are engaged in begging. 26 out of 53 (Male: 18 and Female: 08) get a monthly pension either from Delhi government or from Karnataka (those who are registered in Karnataka).

3.4 PARTICIPANT'S PROFILE

After selecting the colony (as discussed in Chapter 2), social mapping was done based on certain variables like caste, religion, and households with presence of people affected with leprosy. Baseline survey data 2010 from NLR and house listing obtained from colony dresser were also available. Consolidating all three of them, one matrix was prepared in a tabular form which gave information about all household heads (men or women) in the colony categorised under sub headings like language known, age, sex, religion, caste, education, healthy or affected with leprosy, marital status: single, widowed/widower or married, in the case of married couples: both affected, only husband affected, only wife affected etc. This matrix (see table 5) continued to act as a guide while locating and interacting with people in the colony.

Table 5 Matrix depicting participant's details based on certain pre defined variables

	Code	Caste, Religion	Native	Marital Status	Age	Category	Leprosy Status (As in NLR Baseline Data)
Male	MuS	Muslim	Raichur	Widower	58	Old, deformed, widower, wife was healthy, stays with kids	Clawing of both hands and feet with both the eyes Lagophthalmous, ulcer on both feet
	Ya	Hindu, SC	Bellary	Married	71	Old with deformity and ulcers, only he is leprosy affected and wife is healthy, stays with family	Clawing of both the hands and feet. Ulcer on both feet
	Hu	Hindu, SC	Bellary	Married	40	Middle age, wife is healthy, stays with family	Clawing of both hands and clawing of left feet, ulcer on left feet
	Sh	Muslim	Bidar	Married	40	Middle age with wife Jaitun is also affected with leprosy (clawing of both hands and both feet anesthetic)	Clawing of both the hands and right feet. Ulcer on right feet
Female	Go	Hindu, Kurubra (Non Lingayat : Lower caste)	Yadgir	Married	55	Old, Husband Devappa is also affected, stays with husband	Clawing of both hands and feet, toes are amputated, Leonine face
	De	Hindu, (Lower caste)	Gadag	Widow	52	Old, with disability, husband was also affected, stays alone	Clawing of both hands and feet. Ulcer on both feet, Leonine face
	Fa	Muslim	Bellary	Widow	65	Old, with disability, husband was also affected, stays with daughter, son in law and their kids	Clawing of both hands and feet, Ulcer on right feet

	Me	Christian	Banglore	Widow	50	Deformed, stays alone, her daughter and son in law stay in the same colony	Clawing of both hands and left feet, right hand anaesthetic with left eye Lagophthalmous

Among eight research participants, 50% are women and 50% are men in order to ensure equal representation by both the sexes. These men and women were sampled based on the same set of pre-defined variables (Age, Marital status, Religion, Caste, Leprosy status of partner). A brief profiling of all the eight research participants is given below.

Age group: Among four men, two are old (Ya, MuS) and two are middle aged (Sh, Hu). Three women are in their 50's and one (Fa) is 65 year old.

Religion: Among men, two are Muslim (Sh, MuS) and two are Hindu (Hu, Ya). Among women, one is Muslim (Fa), one is Christian (Me) and two are Hindu (De, Go).

Caste: Two men (Hu, Ya) belong to Scheduled Castes and two women (Go, De) are from lower castes (Non Lingayat).

Marital status: Among men, one is a widower (MuS) and rest three (Ya, Hu, Sh) are married. Among women, one is married (Go) and rest three (Fa, De, Me) are widowed.

Leprosy status of the spouse: Among men, three (Hu, Ya, MuS) had/have healthy wives and among women all four have/had husbands affected with Leprosy

Occupation: Among all the eight participants, except for Hu rest all eight depend on begging to earn their livelihood. Six participants (Go, De, Fa, MuS, Ya and Hu) get a monthly pension. Me and Sh do not get any pension in spite of being eligible to get. Me did try to apply for the same but could not succeed.

Economic Status: All the participants are not in good economic situation but still comparatively Hu is far better the others because of his job with MCD. Go goes to beg along with her husband, De is a widow and earns a little by begging. Son in law of

Fatima does some temporary contractual work and she earns by begging. Me's son in law also works in private and her daughter earns by doing tailoring class. I visited houses of all the eight participants. Television set is present in the houses of Go, Me, Hu. Me also has washing machine and fridge in her house. But present of these amenities is not the sole benchmark of their economic status.

CHAPTER 4: LIFE EXPEREINCES OF PEOPLE AFFECTED WITH LEPROSY

NEVER, NEVER AGAIN I CALLED ANYONE A 'LEPER'

"... He limped towards me, half clad in a tattered lungi,
fingerless hands holding a treasured pack to his bosom –
bits of mouldy bread scooped from the city's garbage bins.
Wounds, with dried up puss and blood
made him mean to my eyes.

Too coarse a person for me to accept –
he, a leprosy affected one!!
Insensate dusts of disgust blinded my eyes;
I turned my face away, and called out,
"leper, leper, get away from me..."

- Jacob Oomen

4.1 INTRODUCTION

This poetic verse very aptly gives a glimpse about life stories of people affected with leprosy which revolves around creation of multiple intersecting identities and intense social experiences related with leprosy. Over the years, with slow and very settled routinized forms of violence (necessarily not physical), people who are affected with leprosy actually stop to look at oneself as a 'human being' who is worth being respected, loved, cared and deserves a treatment based on equality. They are unable to think about oneself who has a right to life with dignity. Situations create a dichotomy between the notion of 'worthy and unworthy human being' where people affected with leprosy are seen as someone 'unworthy and with less dignity'. Life is pushed into the darkest corner of the society with a labelling, stereotypes, stigma, mockery of self, abuses hurled at oneself etc. All this is certainly an outcome of their medical condition conjured with their socio-economic background and a particular context. They crave for respect and a life with 'some' dignity all through their lives but it hardly ever comes to few of the fortunate ones. Scourge of leprosy is amplified not because of mere affliction with the disease which is defined bio-medically but also because of the stigma attached to the medical condition in larger public psyche which is ingrained in a historical, social, cultural, economical milieu. This is irrespective of awareness level or education status of people in the larger society[40]. What medical science reveals is sidelined most of the times by beliefs, prejudices and attitudes of the larger society in relation with people affected with leprosy.

It was felt very strongly to start this first chapter of analysis with above written poetic verse. This verse is very apt in accordance with motives of the present empirical work where an attempt is made to state, right in the beginning an underlying sense of a deep craving to be treated with dignity and as a human. This was repeatedly articulated in various ways by people from the field through narrations of their various life experiences. There is a clear consciousness about dignity and right to be treated equal deep down in their lives in spite of innumerable experiences of stigma and its impact in the form of humiliation, devaluation, exclusion and discriminating practices. They certainly want themselves to be freed from the clutches of a 'leprous identity' which overlaps with and transgresses many other identities created in their lives. This identity is created and maintained because of stigma associated with their medical condition in a wider public imagination and its mediation through certain kind of contexts. Process of stigmatization is dialectic wherein binaries of 'them-leper' vs 'us-healthy and normal' are created. This acts as an axis in determining and shaping of various life experiences of people affected with leprosy. Illness becomes a metaphor in their lives making them 'unwanted disgusting ailments' of the society. A component of basic human value is totally lost in their lives.

"*Hum bhi to insaan hain, iss desh ke nagrik hain. Kyon hamein aise dekhna aur bhedbhaava karna*" – (We too are human and citizens of this country. Then why this

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[40] This statement is made after a very long and concrete observation over a long period of time.

discrimination towards us?), is a complete expression in itself which repeatedly echoed in the field. There is a consciousness about the fact that 'our bodies are marked and lives are stigmatized' but yet there is a very meek voice which also affirms the fact that 'we are human and deserve to be treated equal with respect'. But articulation of this voice to the world assertively is something which has been impossible for them because of their position in a web of social relationships which is not only hierarchical but also oppressive. There is a distinct socialization process where nature of relationships is such that people affected are treated as outcasts, segregated, verbally and at times physically abused. Bodily integrity has been violated not only by the disease but also by mockery of the society towards them. People affected with leprosy have witnessed this right from the time when surrounding people realised about their health condition, creating a sense of shame, humiliation, low self-esteem and forced ghettoisation into communes of 'people with shared stigmatized identity'.

In the present empirical work, a deliberate focus has been laid on capturing life experiences of both men and women in order to bring in a gendered understanding about their lives which is articulated by them in their own unique ways. A mix of people from different caste, religion backgrounds has been purposively chosen although class wise almost all are at equal front- poor with very weak financial background. There is relative advantage with marginal differences i.e. one may have ten rupees then another may have fifteen rupees. But all of them are struggling and attempting to strive every single day to the best of their capacities. All seven research participants out of eight, except for **Me**[41] **(name is coded)**[42], are from a rural background (North Karnataka) who have migrated to Delhi for various reasons which will be discussed further. Thus, a mix of purposively selected research participants has been consciously sampled in order to incorporate an understanding based on caste, class, religion, gender which also act as crucial social determinants of health and majorly affects health outcomes among affected individuals and communities. As evident from the literature review, studies across the globe in different settings have confirmed that lower socio-economic life conditions contribute not only to increased vulnerability of acquiring leprosy infection but also further consequences in the life. Here it is important to understand that one is not saying that if you are poor you will get leprosy and if you are not you will not.

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[41] She is from Banglore, Karnataka.

[42] Names of all the research participants and people from the field are coded in order to protect their identities.

Rather it is required to recognize the role played by socio-economic conditions of living in increasing the possibilities of contracting infection and untimely addressal of the same. This is evident from the experiences of other diseases as well across the globe.

In this chapter narratives about different spheres of life of people affected with leprosy have been presented with an analysis. An attempt has been made to deploy a sociological understanding (wherever appropriate) in order to better understand various phenomenon and processes. Section begins with an analysis about linkages that exist between migration and leprosy and various causal factors determining people's choices to migrate. This is followed by a gendered understanding of life experiences of those affected with leprosy keeping in consideration views expressed by both men and women. Third section begins with a discussion about dynamic organic world of a leprosy colony which is very crucial in determining and shaping of social networks of people affected. Final and last section deals an understanding about phenomenon of begging using participant perspective in the context of leprosy.

Certainly, leprosy is one of the key prisms through which many of experiences of people affected with leprosy are filtered through[43]. Thus, through their various narrations which constitute entire life history of each one of them, an effort has been made to document 'their experiences based on their understanding of their world'. In short it is '*Unki kahani unki zubaani*'. As a researcher, I believe that this gives representation to an extent to those mute and weaker voices to narrate what they went through and how life is like for them. For many of the research participants it was like a catharsis to go back to their past life and re-think about the way things happened. It was indeed difficult for them but certainly not impossible. But again, one must acknowledge that always there is a scope for further improvement and so as it is here too.

4.1.1. UNDERSTANDING REFERENCE FRAMES USED BY RESEARCH PARTICIPANTS

It is important, when studying people's life experiences, to be able to try and understand the frames of reference (of changes, key life events, people, time, places etc) used by them. These frames of reference often change in a context that helps in tracing, connecting and thus better understanding people's various life experiences and perceptions. Using these frames of reference participants defined certain of their life

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[43] Staples.J (2011a,b)

events in a very crucial manner. They articulated their views about changes in their health and wellbeing over time using these reference frames which also enables us to understand various factors played out in shaping their health outcomes.

Some of the reference frames commonly used by research participants have been- time when people came to know about the disease in their native place, admission to leprosy hospital and/or shift to leprosy colony. migration to Delhi, key political events like Rajiv Gandhi's time in relation with their time of arrival in Delhi, VP Singh's time in relation with regularization of their colony with legal entitlement over land etc, while narrating their life stories. Accordingly they recalled and constructed their life trajectories.

4.2 UNDERSTANDING LIFE EXPERIENCES OF PEOPLE AFFECTED WITH LEPROSY

At the very onset of the study it's clearly mentioned that key research objective is to understand and document 'lived experiences of people affected with leprosy' residing in a leprosy colony of Delhi with a rendering of a theoretical understanding based on the concepts of stigma and dignity. Certainly these experiences are greatly impacted with one's experiences of stigma and conceptualization about one's dignity. Keeping this objective in consideration, life histories of all the eights research participants were documented making a narrative inquiry.

Here it is important to understand that there is a multiplicity of contexts in which these life experiences of people affected with leprosy are ingrained which consequently have a detrimental effect. Social experience of leprosy at an individual and commune level can be deeply scrutinized under the rubric of social background, economic class and life conditions of poverty, social exclusion and graded inequalities of the society, decision making, power and hierarchies etc. In the present empirical research, an attempt has been deliberately made to understand life experiences of the research participants in a research setting where they actually live (leprosy colony). This enables to understand what is evident beyond obvious i.e. seeing and analysing beyond what they share. An analytical understanding has been developed based on field observations as a researcher and participant's sharing in their very own living set up. This has also enabled to understand family situations, community dynamics and pattern of access to resources in order to understand an overall picture as a whole. Frames of reference used by research participants proved to be a crucial key in order to understand and corroborate a lot of their experiences and narrations.

As the title of this study suggests 'Study of lived experiences of people in a leprosy colony of Delhi[44]', there are multiple intersecting social identities created and hegemonically maintained in the lives of these people. Undoubtedly, this is rooted in a particular context with multiple factors at play. Leprosy is certainly cross cutting identity among all. 'Identities' exist at multiple levels of existence of people affected

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[44] There are eight research participants in this research study. Their names have been codified as follows:
Male participants: Ya, MuS, Hu, Sh
Female participants: Go, De, Fa, Me

(individual and community level). On one hand side, an identity of a 'leper' is stigmatizing at an individual and commune level but on the other hand side existence of this very same identity brings in a shared notion of collective identity and representation. So a situation of dispossession in the context of larger societal processes becomes a situation for dispossessed in social millieu of people affected with leprosy[45].

4.2.1. MIGRATION AND LEPROSY

Inter-linkages between leprosy and migration have various dimensions. A mix of push and pull factors both played a crucial role in determining the choice to migrate and selection of the place by people affected with leprosy and RK Puram leprosy colony is no exception. Search of a livelihood/job, availability of better treatment facilities and other essential services, anonymity of living acted as '*pull factors*' where as stigma (self and enacted both), refusal of employment, turning away by family etc comprised of '*push factors*' from their native place. In Delhi, particularly in RK Puram leprosy colony people have migrated from as far as various districts of North Karnataka. And interestingly, all of them have migrated to Delhi through or with some known contact. There exist some linkages between people affected with leprosy who were already settled in Delhi and those who newly migrated from North Karnataka which actually facilitated migration to Delhi. It is important to note here that all the participants except for **Me** are rural to urban migrants. They have associated approximate time of their migration with Rajiv Gandhi and/or VP Singh's government. One must note that during those days there was no direct train to Delhi from any district of North Karnataka so all the four male participants and others reached Delhi after stopping at multiple places on way and changing their trains. They either came alone or with family or along with some person[46] whom they met in their native place or during their stay in leprosy hospital.

Fieldwork was started with an initial assumption that migration to Delhi from North Karnataka[47] might be a case of distressed migration. This is because North Karnataka[48]

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[45] This was an observation made by James Staples through his ethnographic work in South Indian leprosy colony.

[46] A basic group bonding and positive identification with each other by means of disease began from this point.

[47] As per Dr Venu, administrative medical officer of CL Hospital, Bangalore (lone leprosy hospital in Karnataka) even today they receive leprosy cases from North Karnataka districts, including Gulbarga,

is a drought prone region with widespread backwardness and low levels of human development index (HDI). It lags behind in respect of many indicators in general and almost all human-development indicators in particular. Quality of life is worst and the region is among the most backward in demographic, social and health indicators in the state. As evident from state human development report 2005, situation has not improved much even in the 21st century. Migrants in the two Kannada leprosy colonies of Delhi are from districts of North Karnataka comprising of Bombay and Hyderbad Karnataka (Bagalkot, Bijapur, Gadag, Bellary, Bidar, Gulbarga, Raichur, Yadgiri). Bellary, Bidar, Gulbarga, Raichur, Yadgiri, Koppal are the six backwards districts of Hyderbad Karnataka with a low HDI ranking. Bagalkot, Bijapur and Gadag districts of Bombay Karnataka region are no exception (Karnataka Human Development Report 2005). What one is trying to state here is that situations of poverty and marginalization have historically exited in parts of North Karnataka.

However, from the participants it clearly emerged that 'affliction with the disease and resultant cascade of life events' coupled with existing life situations in North Karnataka played a crucial role in their out migration to Delhi. Else they would have preferred to stay back and continued with their lives back home. Two of the participants, **Ya** aged 71 and **Sh** aged 40 shared very clearly

> *"Hum acche rehna hota toh yahan kyon ana phir itna dooor"* (If we would have been allright, why we would have come so far?).

Lower socio-economic conditions have existed historically in these districts as stated above but 'leprosy status' almost synonymous to one's social status acted as a trigger to the phenomenon of migration by those affected. Reasons for migration of men and women are different but yet inter-related. An analysis below presents various factors which triggered migration by people affected with leprosy to Delhi.

4.2.1.1 MARRIAGE

For women, marriage has been one of the key factors which played a major role in migration. This is accompanied with certain other factors in the case of some other women. In the present research, all the four female participants had migrated to Delhi

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Raichur, Koppal, Bijapur and Bagalkot. There are also many cases from Chikkaballapur, Kolar and Davangere.

[48] North Karnataka not a homogeneous regional unit with Bombay Karnataka and Hyderabad Karnataka areas presenting a distinctly different level of human development.

either after getting married along with their husbands who were also leprosy affected or to get married to a man staying in Delhi who was leprosy affected.

As **Go**, aged 55, shared

> "*Shaadi waqt chatta aya tha. Illaz karwaya tha aur pati bhi Hospital mein saath hata. Baad mein phir Yadgir se Pati saath mein yahan Delhi iss colony mein aa gayi. Akele hum wahan kaise rehna*" (At the time of marriage I had spot. I did get treatment at various places and my husband was also with me. Later I shifted to Delhi along with my husband from my native Yadgir. How I would have stayed there alone?)

Another participant **De,** aged 52, said

> "*Pati ke saath mein Bellary Hospital mein rahi ilaaz ke liye.Wapis nahin ja sakte.Humko pehchaan wala bola Delhi jao karke. Uske baad phir hum dono Delhi ko aa gaye jaan pehchaan karke*". (I stayed in Bellary Hospital along with my husband for treatment. We could not return back home. One of our known person told us to migrate to Delhi. Later we shifted to Delhi through some known contact)

Migration to Delhi can also be because of a mix of push and pull factors wherein marriage plays a key role. Better living conditions, more earnings to run household, enacted and self stigma can also be associated reasons for one's choice to migrate. In the case of women, migration has happened mainly after marriage in spite of these factors existing prior to marriage as well. For 65 year old **Fa,** situation was quite similar to explained above. After she shifted to Bellary leprosy colony along with her husband whom she had met in Bellary leprosy hospital, earning was mainly through begging, teaching work done by her husband in colony school, small amount of monthly pension and sporadic donation activities. As family size increased after adopting one girl child, family needs and expenses also increased. Earning was no longer sufficient. Thus, they mutually decided to migrate to Delhi. She recalled

> "*Bellary hospital mein ek jawan aadmi hate-unko bhi bimari hati par thodi thodi. Jawan ladki kidhar jaegi kya karegi aisa bolke samajh ke hum shaadi kar liya. Kya hai na mia-biwi haat pakad sansaar mein rahe toh sahi hai. Hum dono phir Hospital se Bellary colony mein aa gaya aur wahan jiwan bitaya. Wahan thoda*

> *bahut gujar basar kiya. Phir yeh ladki thi-do se teen hue. Wahan ke kamaye mein gujar basar nahin hota. Mein ghar par hi ladki ko dekhti. Woh phir thoda bade hone se hum yahan Delhi aa gaye pehchaan karke*'. (I got married to one man whom I met in Bellary Hospital. From the hospital both of us shifted to Bellary Leprosy Colony. After adopting our daughter, our expenses also increased. I used to look after her at home. Once she grew up a little we migrated to Delhi through a known person).

Thus in search of a better life which is more economically stable, with basic essential services and an anonymity of living in Delhi from known people back home propelled her and her husband to migrate to Delhi. It's been now three decades since the time she first came here.

For a single deserted woman, life is certainly difficult. In a society like ours where gender relations are highly iniquitous and oppressive, situation becomes even more critical. And in a case where such a woman is affected with leprosy- a highly stigmatized disease, life is even more vulnerable. **Me,** aged 50, a resident of Bangalore has been one of those women. She was deserted by her first husband and was sent to Delhi to get married to another leprosy affected person who was staying in RK Puram Leprosy colony. She recalled

> '*Mera pehla pati na mujhe leprosy aane baad chod diya. Bacchi saath lekar mein akele kya karna. Woh pehchaan wala Uncle Delhi jane ko bola. Yahan akar shaadi kar liya. Mera dusara pati ko mere jaisa leprosy tha*'. (My first husband left me after the onset of disease. I was left along with my two children. One known person – my Uncle, asked me to shift to Delhi along with my children. I came here and got married second time to a man who was leprosy affected like me)

Having said that now we move on to next section which looks at other factors involved in people's choice to migrate from their native place.

4.2.1.2 In search of a livelihood

In general, rural to urban migration in search of a livelihood is no new phenomenon. Urban areas attract many from rural areas because of a wide range of opportunities available to earn a living and especially when the state/region from where people migrate does not give much option for the same. Certainly, North Karnataka fits into this category where there were limited livelihood opportunities for people affected with leprosy not only because of overall low level of conditions of living but also because of the disease they were afflicted with. It is important to note here that all of them migrated to Delhi during 80's and 90's. As revealed by people from the field. in their native villages and even in smaller towns like Bellary opportunities for earning were really not available. They were easily identifiable because of the disease they had and refused to be given any work. In the realm of no option to earn a living, begging was only choice left for them amidst circumstances of despair and need. Being in the native place it was not easy to beg either as they had fear of getting identified. In such a situation. prior existence of known people from the region in Delhi who were also affected with leprosy acted as a major support system in an alien place. On one hand side there was desperation of earning a living and surviving in their native place and on the other hand side, there was a hope of availability of opportunities in Delhi along with a better living and presence of known people with whom they could connect because of a shared identity.

Undoubtedly, Delhi is a big city with plenty of options available offering not only anonymity of living and earning but also better living conditions. It repeatedly emerged from the field that they (people who had migrated to Delhi) did not share with their relatives and other known people in Karnataka about what do they do to earn a living. In the absence of any dignified means of earning even in Delhi, all of them were compelled to start begging. Men were either denied work because of the disease or incapacity to work because of repeated ulceration and wounds. Of course, in contradiction to what they hoped before migrating, there were no better work opportunities available for them even in Delhi. But certainly it was better in many senses. In conformity with gender roles and activities, women were expected to be at home to do domestic and care work. But in an absence of livelihood options, social security net and inability to meet with daily essential needs, all of them (men and women) were siphoned off to begging. Women not only begged but also did household work and taking care of the family. **Hu**, aged 40, has been comparatively few of the fortunate ones who could at least get a temporary job of sweeper with Municipal

Corporation of Delhi (MCD)[49]. But he too started his life in Delhi by begging for initial few years.

Migration in search of a livelihood is reiterated through the narratives of research participants. As shared by female participant **Fa, aged 65,**

> "*Wahan ke kamaye mein gujar basar nahin hota. Mangne ko bhi log dekh lega karke lagta. Bahut mushkil hua. Kaam bhi nahin koi. Kya hona parivar ka phir. Mein ghar par ladki ko dekhti. Woh phir thoda bade hone se hum yahan Delhi aa gaye pehchaan karke. Gujar basar toh karna hota na.*" (Over there it was very difficult to live a life. There were no options for earning. I could not even beg else people would have recognized me. I could not work either. Managing family was getting difficult. My daughter was also growing and I used to look after at home only. Finally when she grew up a little we migrated to Delhi through our known contacts. After all, life has to be managed)

Similarly, **71 year old male participant Ya** expressed

> "*Kheti chod diye. Karnatak se idhar aa gaye kyonki kahin toh jina padega na. Kama nahin sakta tha. Khana ko mushkil tha. Basa bimari hua na uski vajah se hum Delhi ko aa gaye. Yahan hamare jaisa log hai na*"(I had left farming and came to Delhi because I had to survive. I was not able to earn and difficulties were immense. All was because I got the disease. I came to Delhi since our people were staying here from before)

For **Ya,** multiple factors acted in unison. Because of the disease **Ya** could no longer do farming and as disease progressed his productivity reduced even more. Presence of the disease and frustration of not being able to work along with stigma attached with his condition compelled him to finally leave his village and migrate to Delhi. Even after reaching Delhi he could not find any work because of his deteriorating condition. So he started begging to make his ends meet and depended upon charity and donations given in the colony. Here at least embarrassment of being noticed and recognized by known people was not there. He could certainly earn a living anonymously by begging which is much more than what he could earn in a day in Karnataka.

Another participant **Hu, aged 40,** clearly mentioned

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[49] In this colony only seven people are employed with MCD- All as sweepers on a temporary basis.

> *"Deformity aa gaya tha. Sab kama tha aur hum baith ke khana accha nahin lagta. Humko sharam lagne laga ki woh log kamana aur hum kaise khana baith kar. Hamien bola ki wahan chale jao aur kuch naukri wagarah bhi mil jaega. Bacche bhi acche se padd likh lenge. Sab kuch thik tarah se hoga. So hum aa gaya yahan naukri ki talaash mein'"* (Deformity had started to appear. Everybody at home used to earn and I could not. I did not like this. I was told that go to Delhi. You will be able to get some job and all will be fine there. Children also will be able to study well. So I came here in search of a job).

Frustration on account of not being able to work and economically unproductive in native village has been immense with people like **Hu and Ya**. They used to feel embarrassed of themselves for being unproductive because of no options available to earn a living in the native place. They wanted to earn and be self-dependent rather relying on somebody else.

4.2.1.3 Stigma faced in native place

As stated in introductory paragraph, stigma acted as a major push factor for people affected with leprosy which played out in their lives in unison with other push factors. Enacted stigma was exhibited by neighbours, people in the native village and in some cases even by family members. Lack of job opportunities, stigmatizing behaviour and attitudes, bodily complications, humiliation caused on account of constant rebuke and discrimination- all lead to a deeply internalized dehumanized feeling over the years and generated self-stigma. They were treated like untouchables in their native on account of the disease with deformed and marked bodies. Once they landed in leprosy hospital for treatment, there were no options to return back home mainly because of stigma and humiliation, in some cases even detachment from the family members. Only option left was to migrate to another place in the realm of no earning opportunities, poor living conditions. Prior existence of known people from North Karnataka in leprosy colonies of Delhi acted as a hope and a means to pull in other affected people. A new community was getting crystallized in Delhi with more and more people of 'similar kind'[50] joining in.

Life in Delhi has been comparatively better since constant rebuke, covert forms of violence and humiliation did not persist in very severe form and biggest of all – Delhi

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[50] This is the distinction expressed by people affected with leprosy themselves.

gave them anonymity and a community level binding. Stigma certainly prevailed in their lives even in Delhi but certainly in less severe forms. For people affected with leprosy who had migrated from Karnataka, life in Delhi presented a life which was comparatively better. Moreover, there was a unity of numbers too because all of them commonly bonded through a stigmatized disease identity and a cultural similarity.

Admission in leprosy hospital proved to be one of the key life events for the research participants and at large for many others. From here onwards their life trajectory changed in terms of shifting and migrating to a different place either after the completion of the treatment or in between. Stay in leprosy hospital provided an opportunity to the participants (those who stayed) to gel with others who were also affected with leprosy and create their own small little network of known familiar people. One of the participant, **MuS, aged 58**, had expressed,

> *"Daag aane ke baad mein Banglore mein admission kara liya CL Hospital, Magdi Road, Bangalore mein. Ilaaz hona baad mein wahan se Bagalkot mein ek saal raha, Hubli mein 2 saal. Phir train se Delhi aa gaya kyonki yahan hamare desh ke bahut se log hain* "(I got admitted in CL Hospital, Magdi Road in Bangalore after the appearance of spots. After finishing the treatment, I stayed in Bagalkot for a year and in Hubli for two years. Then I came to Delhi by train because here many people from my state and of my kind were staying).

71 year old, Ya, was compelled to leave his native along with his wife and children. As the disease progressed and started to become visible, people started objecting and life was even more difficult because of no means of earning. His family was socially boycotted. Tired with humiliation, rebukes and struggles of everyday, he decided to migrate to Delhi with his family. He recalled

> *"Log aitraaz karta tha humko aur maa baap ko. Kuch kaam bhi nahin kar sakta. Humko naraaz ho gaya. Accha nahin lagta na roz roz. Sara chod hum yaha aa gaya phir"* (People used to object me and my parents. I could not do any work also. I did not used to like rebukes of everyday. I was annoyed and left everything to shift to Delhi).

One of the female participants, **Fa aged 65** shared along the similar lines. She recalled

> *"Dawai Daru chala. 20-25 saal mein udhar hi khede mein hati. Par mein wahan rehne se meri behno ko koi shaadi nahin karta. Ghar par koi nahin ana jana. Maa baap log ko Bellary mein Hospital ka pata lag gaya aur wahan par chod diye. Tab mein tumhare jitni umar ki hati"* (My treatment continued and for 20-25 years I was in my village only. Because of me being there nobody was willing to marry my sisters. My family was socially devalued-people stopped visiting our house. My parents came to know about Leprosy Hospital in Bellary and they left me there. I was quite young that time)

Coming to Bellary leprosy hospital was indeed a life changing event for her. She not only got treated but also met her life partner. Later they got married and shifted to Bellary leprosy colony and from there to Delhi in few year's time along with their little daughter.

Male participant, **Hu aged 40**, had another story to share which presented a good mix of hope and despair, ultimately determining and shaping his choice to move to Delhi with his wife and children. His family members were indeed very supportive of him but he was immensely disturbed with stigmatizing behaviour and attitudes of outside people towards him. He used to feel embarrassed for being economically unproductive although none of his family members ever rebuked him for this He recalled

> *"Pados mein bhi sab log ko pata lag gaya aur aitraaz karna shuru kar diya. Yeh sab soch humko mind mein thoda dhila ho gaya. Sab kuch chod hamara mann pura aisa ho gaya aur idhar (Delhi) mein ghumta phirta aa gaya'* (People in the neighbourhood also came to know about the disease and started objecting. I was immensely sad. So I left everything and came to Delhi).

People like **Hu** present a strong case for push and pull factors acting in unison in order to determine and shape people's choice to migrate (here to Delhi). His family members were indeed very supportive of him including his parents and brothers but the pain of being stigmatized with attitudes and behaviours of outside people was piercing and heart wrenching for him. But in spite of all that he did aspire for a better life in a city like Delhi for the sake of his wife and children. He had heard from his know people about life in Delhi. In Delhi he could not only earn but could also afford to have better life conditions for his family in a slow and gradual process in comparison with what he would have been able to achieve back home. There was an entire imagination about city life in his eyes when he migrated to Delhi. All he knew that time was stay in Delhi could give him and his family a better life in spite of his affliction with leprosy. Hope to be economically productive and known contacts motivated him to choose this particular city only as his first and last choice. Thereafter, there was no looking for him ever.

There are multiple stories of different people within this colony. Some bear similarities with others with a distinctness of their own also. Each of the life stories are unique in itself. But a common reality for all is that they all are migrants from North Karnataka which was done under certain compulsive situations. All the research participants have been in Delhi for almost past two decades. But reasons which existed for an initial decision to migrate to Delhi were very person specific. Take the case of **Sh aged 40**. He shared

> *"Bimari bahut ho gaya. Ma-Baap koi nahin. Bhai bhi shaadi baad alag ho gaya. Bahut taklif thi Karnataka mein uss time par. Mang mang kar jivan chal raha tha. Yahan (Delhi) par mil gaya rasta so idhar aa gaya. Hum akele hone ke baad aage aage karke Delhi aa gaye. Aise koi jaan pehchaan wala tha*" (Disease had progressed a lot. Parents were not alive and brother also separated after his marriage. Life was very difficult during those days in Karnataka. I used to beg and earn a living. I came here along with one person and found a way here in Delhi).

Sh had migrated to Delhi along with one person whom he met in Bellary leprosy hospital. Feelings of complete hopelessness and alienation from his native place were deeply fathomed by him. Intense stigmatizing experiences and lack of the presence of any of his blood relatives aggravated the situations for him. He reached Delhi in three months time after stopping at various stations and changing trains. He lived as a homeless, slept at railway stations and on footpaths during the course of his three month long journey to Delhi.

4.2.1.4 IN SEARCH OF BETTER TREATMENT FACILITIES AND OTHER ESSENTIAL SERVICES

Based on the field experiences (in RK Puram leprosy colony and other colonies in Delhi at the time of exposure visits), it clearly emerged that most of the migrants to Delhi are from leprosy endemic states like Orissa, West Bengal, Bihar, Some districts of UP, Karnataka, Tamil Nadu etc. A lot of them are from districts/regions where there were no adequate health facilities, basic essential services and adequate means of livelihood.

They had to survive and thus migration to mega and metro cities including Delhi was inevitable.

Particularly about Delhi, they (people affected with leprosy who were yet to migrate) had heard from previously settled people from their region about availability of good treatment facilities and presence of government schemes like monthly pension to people affected with leprosy, and good education facilities. Regularization of the colonies with 24*7 free water supply and electricity along with legal entitlement over land by mid 1980's facilitated in-flow of more people. This was detrimental for people's decision to stick to the place and settle down permanently.

One of the participants, **Hu aged 40**, shared

> "*Chota gaon mein swasthya ka kuch suvidha nahin milta hai. Usase zyada yeh bimari ho sakta hai. Bacchon ka padai likhai ka bhi into nahin hona.*" (In small villages health facilities are unavailable. Because of this disease progresses even more. Education facilities for children are also inadequate).

Hu's sharing is self explanatory in terms of what is stated above.

Thus, from all above narratives of research participants it is clearly evident that there was a mix of push and pull factors which acted out in determining and shaping of their choices to migrate to Delhi. It is important to note here that these colonies are regionally or state-wise grouped. Admission to leprosy hospital proved to be a major life event where they either found their life partner or some known person along with whom they migrated to Delhi. It was an important place to build their own kind of social networks. Prior existence of people affected with leprosy in Delhi acted as a major support system for the new ones who migrated. All of them migrated to Delhi and slowly settled down here in leprosy colonies gaining a community identity with common shared identity. Certainly, a slow and settled process of ghettoisation was in play. All the boundaries of caste, religion, class withered away here once they all started inhabiting together. Leprosy became their only religion. Inter-caste, inter religion marriages are very common and almost all are either within the same colony or with people from other leprosy colony of Delhi who are from the same region or with people staying in leprosy colonies of their native state. But it is important to note there that in spite of all this binaries do exist in these colonies like poor vs poorest, married vs widowed. This may not be visible very easily to the world outside. Most of the people residing in leprosy colonies including RK Puram leprosy colony are not original residents of Delhi. Although they have been staying in the city for past many years but still the tag of a 'migrant' is not removed. This is illustrated from the fact that still none of them have a voter ID card of Delhi. None of the people affected with leprosy nor their healthy dependents have below poverty line (BPL) card and ration card. Residence proof is still not there in spite of a house in Delhi. It is not just an identity of 'person affected with leprosy', it is also an identity of 'migrant' with which they are living and struggling with on everyday basis.

4.2.2 GENDER AND LEPROSY

Critically understanding and analysing gendered impact of leprosy in the lives of those affected by it is very much essential. Certainly leprosy affects both men and women in different ways which creates vulnerabilities in its own peculiar ways. Knowing and understanding the same with their perspective is very much essential. Sociologically speaking, there are gender roles and responsibilities, norms in a society; distribution of resources, cultural practices etc which impact to a great deal social experience of leprosy among men and women. Here a deliberate attempt is made to render a gendered understanding to experiences of people affected with leprosy rather than comparing experiences of men and women. As a public health practitioner, it is important to recognize gender as one of an important social determinant of health in the lives of those affected with leprosy.

Take the case of a developing country like India where society has widespread gender inequalities and power hierarchies which have existed historically and contributed in shaping of gender relations. There are various means of enacting institution of patriarchy with very diverse implications. This certainly plays a crucial role in the domain of stigmatized infectious disease like leprosy as well. For a woman, affliction with leprosy coupled with lower socio-economic background acts as a crucial axis of creating multiple vulnerabilities. In cases where deformity visibly starts appearing, experiences of stigma and indignity have worst forms of impact especially upon women. Decision making power or even say in decisions is seldom in their hands. As per societal norms she is expected to abide with roles and responsibilities decided for her. She is expected to get married and responsibly carry out her roles and responsibilities of domestic and care work. Access to economic and other resources is seldom in her hands. She is expected to function normally in spite of ill health and complications on account of leprosy. So even if a patch appears on her body, she is either socially conditioned to ignore it, be mute about her pain and suffering or even if she reports ultimate decision is made by her family members or husband. After marriage, she is expected to be a mother at an earliest. It is scientifically known that during pregnancy and lactation period, a woman undergoes immune-suppression and this is the time when her signs and symptoms related with leprosy advance if priorly untreated.

With **50 year old Me** situation was the same. Her disease intensified after the birth of her first child. She said

> "*Shaadi pehle bimari tha thoda thoda. Ek baccha aya- ladka hone baad bimari aur bhad gaya. Pura sharir par aise aise ho gaya. Goli wagarah kuch nahin liya tha tab tak*" (I had disease in a mild form before my wedding. After I had my first child, my disease progressed much more. It spread onto entire body. I was not taking any medication that time)

All above mentioned situations and factors play out in shaping health outcomes of women affected with leprosy. This has clearly emerged through various informal talks with affected women of the colony including four research participants as well.

Another illustration of roles and responsibilities defined for a women as a home-maker taking care of domestic work is evident from the narrative of **55 year old Go**. Although she shared her typical day schedule but her gendered role and responsibilities were evident from her narrative. She said

> "*Mein mangne ko subah 6 baje jati hoon pati saath. Dupahar mein akar kahan bana aur khilakar, ghar saaf kar phir 2 baje jate. Shyam 5 baje tak wapis akar khana bana, khilakar aur tv dekh so jati. Khana banate waqt dhyan rakhna hota- garam pata nahin chalata haath mein. Nahin toh jal jata*" (I go to beg at 6am along with my husband. We come back in afternoon. I cook food, feed, clean house and then leave again at 2pm. We return by 5pm. I cook again, feed and watch TV. While cooking I have to be careful since I cannot get sensation of hot and it may burn my hand)

One of the male participants **Sh aged 40** shared in this context about his wife who is also affected with leprosy. But he does share some responsibilities with her in household work which was rare in other cases.

> "*Woh bhi kodi hai. Pairon aur ungli par thoda zakh rehta hai. Kaam woh hi karti hai ghar ka saara. Dono toh hum hain. Mein bhi dekhta hoon thoda kaam khana pakane ka wagarah*" (She is also a leper. She has ulceration in her hands and feet. She does all household work. But I do help her a little in cooking)

If she is unmarried, for her best interests, parents either conceal or pay no attention to appearance of any kind of signs/symptoms of leprosy. Attempts to access treatment or report the same leads not only to social mockery and osctracization of the family because of stigma but also unwillingness of any man to marry her. And an unmarried girl especially in a rural area is a big taboo even today. There is another field situation as well- even if a woman is able to marry a healthy man after concealing her leprosy status, as soon as man comes to know about it, she is deserted. Life situation of **Me aged 50**, is exactly similar to what is stated above. She was deserted by her first husband as soon as her disease progressed and he came to know about it. She said

> "*18 saal par mera shaadi ho gaya. Mera pati accha tha. Hum love marriage kare the. Shaadi baad bimari zyada ho gaya. Pehle pati acche hona na toh woh chod diya mujhe*" (I was married when I was 18. We had a love marriage. My husband was healthy. But after marriage, my disease progressed considerably. Realizing this husband left me).

Or if her leprosy status is known among people then only option she is left with is to marry a man who is also leprosy affected and might be much older also in certain cases. In this context, narrative of one of the female participant is worth mentioning. **Fa, aged 65,** shared

> "*Wahi Bellary hospital mein ek admi ko mile hate. Unse shaadi kar hum biwi pati hokar sansaar chalaye. Woh bhi bimari ke the- akele hate aur mein bhi. Woh bhi akele aye the. Aisa bolke hum dono shaadi kar liye. Koi aur toh humse shaadi karta nahin hata*" (In Bellary leprosy hospital I met a man who was also affected with leprosy. We got married and started staying together thereafter. No one else was willing to marry me).

One of the field realities which was repeatedly encountered in the field was- many of the women affected with leprosy were widows. (both in younger and older age groups). They were left with no option after the death of their husbands (affected with leprosy) except to live a lonely life without any prospects of second marriage. Other colony women who had their husbands alive used to look at these widowed women with disgust or with extremely negative labelling. Although these women affected with leprosy used to speak it in a lighter vein but deep down disappointment on account of the same was reflected. I often heard in the colony one particular sentence from women (including research participants like De) who were widowed. They used to point out at younger healthy small boys, laugh and say

> "*Yeh ladka hai na....isse mein shaadi banungi. Mera pati banega*!!" (I will marry this boy. He will be my husband)

All the women affected with leprosy whom I met in the field are married to a leprosy affected men only. None of them have a healthy husband. Narratives of female participants like **Fa, De, Me** suggest the same.

De aged 52, mentioned

> "*Bellary hospital mein admission time par meri shaadi ho chuki thi. Mera pati ko bhi bimari thi. Woh mere saath hi rahe the wahan 2 mahina*" (At the time of admission to Bellary hospital I was already married. My husband was also affected with leprosy. He also stayed with me in the hospital for two months).

Me has been the only woman who could marry second time but with a leprosy affected man only. She shared

> "*Yahan par ana bad mera dusara shaadi ho gaya. Unko bhi bimari tha. Umar unki 40-45 ahi hogi tab. Issi colony se the. Mujhe mera Uncle ne bol diya ki Delhi jakar raho- wahan shaadi ho jaega*" (After coming here to Delhi I had a second marriage. He too had leprosy. He was 40-45 year old at that time and was a resident of this colony. My Uncle had told me to go to Delhi and get married there).

There are so many permutations and combinations in a woman's life affected with leprosy and she is the one who is ultimately at the receiving end. But for men, situations are far different which will be discussed further.

In all the situations stated above, if a woman affected with leprosy is from a rural background, with low level of education and lower caste-class background, her voice is silenced forever in most of the cases. This was evident from the field as well where all the women participants were from lower caste, poor households with no or very low level of education. Empowered sense of self is actually missing in the realm of existing situations and her dignity is completely destroyed on account of her vulnerabilities and diseased identity and body. Gender disadvantages created on account of existing gender inequalities certainly affected rates of case detection, treatment adherence and reversal reactions among female leprosy patients. It repeatedly echoed from the field.

Take the case of **Go aged 55,** where deformity could have been prevented with timely attention but by the time treatment was initiated it was too late for her. She narrated

> "*Karib 40 (at the age of 15) saal pehle yeh bimari mujhe aya tha. Mein Raichur hospital gayi dikhane. Phir mein Hyderbad Kukadpalli mein ek hospital mein gayi pati saath apna pair dikhane ke liye. Uss par kuch gir gaya tha aur ghaav ho haddi dikhane lagi thi. Wahan doctor ne surgery kar mera pair ki ungliya kaat thik kar diya*" (Some 40 years back I got afflicted with leprosy. I went to Raichur hospital for treatment. Then I went to another hospital in Hyderabad along with my husband to show my feet. Something had fallen over it and it was burnt with ulceration. Bone was visible. Doctor corrected by feet after amputing all my fingers).

Sharing by another female participant, **Me aged 50**, clearly illustrated the fact that in spite of her signs and symptoms visible not much attention was paid to her till the time she was 20 after which she started Dapsone therapy. But by that time it was too late, deformity was visible and ulceration was intense. **Me**'s case was a clear situation of neglect to her suffering, signs and symptoms. She recalled

> "*15 saal ki thi mein jab bimari shuru hui Bangalore mein hi. Bahut dino tak meri maa ko kuch pata nahin. Bhai, Didi bhi kuch nahin kake liye. Papa mere chote mein hi mar gaye the. Baad mein hai na 20 saal ka hua tab gloi khana shuru kiya.*

> *Bahut ho gaya tha bimari.Shaadi bhi ho chukka tha*" (I was 15 years old when for the first time signs and symptoms of leprosy started to appear. I was in Bangalore that time. My mother did not know anything that. Brother and sister also did not pay much attention. My dad had passed away when I was small. Finally when I was 20 and married, my medication was started. But disease had progressed a lot by that time).

It is important to mention here that gendered understanding about health of the people does not mean health of women alone. It also comprises of factors impacting health outcomes among men as well who are affected with leprosy. Gender differences can be markedly recognized at two levels among people affected with leprosy: At the level of treatment disavowal, concealment and consequent delay in diagnosis which in turn influences treatment seeking behaviour. At the second level, there is stigmatization process associated with the disease which is ingrained contextually. Impact of the same is of very distinct nature both for men and women.

Gender roles and responsibilities are distinctly defined for men also who are affected with leprosy. Men are socially expected to be wage earners and take care of the family economically. They have been more mobile than women and involved in hard manual physical labour especially in a situation when education level has been low and belong to a lower socio-economic background. Exposure to physical labour certainly aggravated their existing situation by causing ulceration, wounds and more deformity. This is a typical situation which existed for male research participants. In this context, one of the participants **Ya aged 70,** shared

> "*Gaon waalon ne aitraaz karna shuru kar diya tha. Mere ko bahut naraaz ho gaya. Kheti chod diye. Sara chodkar mein idhar Delhi aa gaya kyonki kahin toh jnia padega. Kama nahin sakta tha. Kahna ko mushkil tha*" (People in the village started objecting me. I was very annoyed. I left farming. After leaving everything there I came to Delhi since I had to survive. I couldn't earn there, even getting food was difficult).

Another participant **MuS aged 58** brought in an interesting dimension in terms of difference in clothing between men and women and its relation with leprosy. According to him, men have a kind of clothing which can not actually hide their patches even if they want to. While women are mostly indoors and can conceal patches etc owing to the nature of their clothing. He said

> "*Hum admi log ko toh kya kapda aisa hai daag nahin chupa sakta na. Pura baju ka nahin hota. Par aurat log toh ghar par hi rehta hai. Woh apan kapda wajah se bahar log se chupa sakta hai*" (We men have such a clothing that even if we want to hide patches we cannot. But women stay mostly at home and their clothing are such that they can hide patches).

In the context of marriage, institution of patriarchy in a particular society clearly plays out. A man affected with leprosy still has a choice and possibility of getting a healthy wife but a woman affected with leprosy has no choice except to get married to a leprosy affected man alone. This is clearly evident from the field where all the four women have leprosy affected husbands. This is a general reality in the colony. Where as in the case of men, **Sh** is only male research participant who has a leprosy affected wife, rest all have healthy wives. For other men in the colony, situation is of mixed type- they either have a healthy wife or leprosy affected (very few cases) and in some cases very younger to them also. An average gap between ages of husband-wife in this colony is 10-15 years. This was found out after analysing house member details of each of the houses in the colony. In this colony, in most of the cases wives are healthy as it became clearer after visiting each house in the colony. Food for thought here is availability of choices to get a healthy wife in spite of affected with leprosy. **Ya, Hu, MuS**- all three male research participants are leprosy affected but yet they have/had healthy wives. **MuS's** wife was much younger to him (in her 20's) but now she is no more. This situation is true even in other colonies which I visited as part of my preliminary area visits.

Even in terms of articulating life stories including experiences of stigma, men were more articulate then women. In society, women are conditioned right from birth to be submissive and quiet about their pains and miseries. So even when I tried my level best as a friend and a researcher to make women speak up, they hesitated to share. It was only after multiple numbers of visits over the months that they actually started verbalizing their experiences and emotions. But with men, articulation was not a major problem. They freely spoke and shared except for the times when they were unable to understand certain things. It is necessary to mention here that even in this articulation by men, there were variations in terms of 'who could do with much of ease'. I see this ingrained in power dynamics within the colony. On one hand side, some male folk affected with leprosy like **Tho, IbS, DS** and research participants like **Ya, Hu** were quite articulate but on the other hand side people like **Anj, Ra, Ba** and research participants like **Sh, MuS** etc were very less articulate and expressive about their experiences. They actually struggled and comparatively took more time to verbalise the same. People like **Tho, IbS, DS, Ya, Hu** have been the members of Panchayat which gives them decision making position and financially more stable as compared to others while people like **Sh, MuS, Anj, Ra, Ba** have been living in extremely poor situations and with no decision making position in colony matters.

There is another dimension to gendered understanding about experiences of people affected with leprosy as discussed in the previous section- Migration. Men in the society are expected to be economically productive with onus of family responsibility. In the native place (North Karnataka) there were absolutely no opportunities for all affected men including research participants. This was coupled with experiences of intense stigma. Thus, the best available choice was to migrate to another place in a hope to get some livelihood. Situation for women was different again ingrained in gender relations. All affected women including research participants had migrated to Delhi either after marriage with their husbands or to get married to men who were also affected with leprosy. Narratives of all the four male participants reflected the same.

Towards the end in order to summarize entire idea one can look at work of Tolhurst.R et.al. (2002; 135). It was very appropriately stated that

> "*Gender identities, status, roles and responsibilities influence vulnerability to disease, access to health care, and the impact of disease for women, men, girls and boys. Women's and men's roles affect their risk of infection with specific diseases, whilst gender relations influence their ability to protect their own health. Gender differences in access to and control over resources, in decision making power in the household and in roles and activities can limit women's ability to access health care for themselves and their children. Gendered norms and identities influence both women's and men's willingness and ability to seek care. The social consequences of infectious disease are often more severe for women than for men, and illness imposes a particularly heavy labour burden upon women*".

4.2.3 SOME REFLECTIVE INSIGHTS FROM A MINI LIFE-WORLD OF PEOPLE AFFECTED WITH LEPROSY RESIDING IN A LEPROSY COLONY

4.2.3.1 LIFE IN A LEPROSY COLONY: CASE OF JEEVAN DEEP KUSHTA ASHRAM, RK PURAM

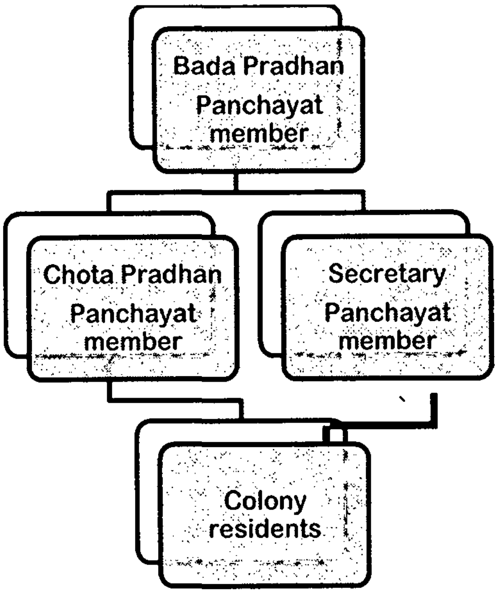
In the present context of increasingly polarised world impacting settlement patterns of populations, leprosy colonies present a classic example of *sarva dharma sadbhaava* (Indian saying). These colonies are of course socially ghettoised because residents have no other place to go either. One can find people from all castes, religions, class, states staying together and harmoniously in these leprosy colonies. Regional segregation may also exist in some i.e. people affected with leprosy from the same state or region residing together.

All affected residents of the present colony were compelled to leave their native places in sheer desperation. Life today is certainly a far cry from the wilderness that they staked almost two-three decades back while leaving their native houses. Undoubtedly, Dapsone Monotherapy and later Multi drug therapy (MDT) medically cured them giving a non-infectious status by the medical doctor. But after being cured or discharged from leprosy hospitals in native place, they found out that society was unwilling to accept and accommodate them back. Life was at cross roads where they could neither return back nor be very confident about future. Only ray of hope amidst such circumstances was information about prior existence of some known people affected with leprosy in Delhi which subsequently pulled them also. RK Puram leprosy colony gave them a new place to stay with differentness in life. Here relations were formed not on the basis of blood but on the basis of one common shared characteristic- all were affected with leprosy. This feature bonded all of them together like one big family. But this is certainly not as homogenous as it appears from outside. Insights gained from intensive fieldwork in this particular leprosy colony and other colonies revealed that there is certainly a group dynamics, existence of hierarchies, hegemonic structures even within these colonies which are very obvious to exist also. Binaries exist based on relative advantages like 'widowed and single vs married', 'panchayat members vs colony members', 'men vs women', 'very poor vs poor' etc.

People who are affected do face lack of employment opportunities but their healthy dependents who reside with them go for work in surrounding areas. Take the case of RK Puram Leprosy colony. It is true that none of the people who are affected have any employment except for those seven people who work with Municipal Corporation of Delhi (MCD) as contractual sweepers. But healthy dependents of all these affected people go for work in surrounding areas although not very sustainable but some petty tasks to make a living. During one of the discussions people shared range of places they go to for work like photocopy centres in Munirka, nearby shops, as housemaids, cleaning staff in hospitals, driver etc.

These leprosy colonies including Jeevan Deep Ashram have their own system of governance where in elected members constitute a *panchayat*. It is very interesting to note about its constitution, features, powers, ways of operation etc. Members are elected on yearly basis with consensus of all colony residents (women may not have a very prominent say). Head of the *panchayat-Bada Pradhan* can continue with his second term also depending upon colony resident's opinion and his overall performance. Only males are part of *panchayat*. Administrative structure of this body is as follows: *bada pradhan*, *chota pradhan*, secretary and other *panchayat* members (see figure 4). They have a monthly meeting towards month end to discuss and resolve colony issues. In the beginning of every month they have a '*committe dalna*' where residents who can afford deposit a monthly amount to *panchayat* as a reserve amount to be used by them in times of need or to pay back loans. This amount can be confiscated also under conditions of inability to pay back loan.

Figure 4 Administrative structure of leprosy colony



Donation and charity activities in general are in plenty in Delhi. In RK Puram leprosy colony it is even more because of the kind of location in South West Delhi- one of the most affluent districts' of Delhi. This was shared not only by residents but also by organizations working on leprosy in Delhi. It is important to analyse and distinguish between donation and charity activities rather than using them synonymously. Donation is a philanthropic activity by people who can afford to do the same while charity activities are driven with religious beliefs and scriptures. Any kind of donation or charity which comes to the colony is equally distributed among all houses and if amount/quantity is less, it is collected and re-distributed after acquiring sufficient amount in the next round. A bell is rung by one person to inform all the houses that donor has come. Food distribution which comes from charity happens near the colony temple.

Sometimes people from adjacent Ambedkar Basti also join in to collect food which is given. According to *Chota Pradhan* of the colony,

> "*Hum unhe nahin rokte. Ata hai to ane deo. Khana sab ko dena acha*" (We do not stop them. If they come we allow them. Food is for all).

There were five such occasions when I observed the same in this colony. Foodstuffs like samosa, pastry, banana, kachori, laddu, pettice, sometimes dal rice or vegetable chapatti etc were given. Basic staple food items like daal, rice, chappati were given less often while other kind of food items were given quite often. People from outside were often found to comment as

> "*Inko kya kami hai khane pine ki. Aata hi rehta hai jab dekho tab*" (They do not lack food. Food is in plenty for them)

But it is very important here to critically analyse nature of foodstuffs given and to what an extent hunger is nutritiously satisfied. Dignity in receiving such donated food is also something which needs reflection. This will be discussed in detail in Chapter 6.

If donation or charity comes in material form like blankets, pulses, rice, clothes, mattress, utensils- distribution happens in common park attached with the colony called as '*kodhi park*' (as called by residents) in the presence of some responsible colony person. Sometimes donors sponsor one time or two time meals depending on their capacity. Raw material is given and food is cooked by colony residents themselves. I observed this activity at different times. There was clear division of labour between men and women. Women did peeling and chopping of vegetables while men took charge of cooking. None of the people who were affected participated in cooking process since younger folk took care of the same.

Here it is interesting to mention one phenomenon[51] which was observed during various other instances too. People of the colony and residents of surrounding area (Ambedkar or RK Puram slum just outside the colony) share a mutual give and take relationship. This symbiotic relationship is for the benefit of both. For example, pulses, sugar, oil, nuts, rice, flour etc is donated in plenty to this colony. Since these food items have a shelf life beyond which they get spoiled so storage is not possible for very long durations. In current times of high inflation where food items are also no exception it is impossible for the poor to buy pulses, oil, rice etc. So people from adjacent colonies or slums buy these food items for a lower price from people in the colony. Thus, colony residents get to earn a little amount extra by selling excess food items they have while residents from adjacent localities get these food items at a much lower price. Its profitable situation for both amidst situations of poverty, inadequate state welfare mechanisms, corruption etc. Similarly, blankets and mattresses which are donated to the colony residents are also sold to one lady agent through *panchayat*. All the blankets and mattresses are collected from each participating house and sold to lady agent. These are

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[51] Same was observed in leprosy colony of Peeragrahi and Lajpat Nagar too.

sold at absolutely minimal rate like Rs 20 for thinner ones and Rs 40 for thicker ones. Amount generated is equally distributed among all later on.

Each colony has few *'panchayat houses'* i.e. houses which are empty are in the custody of *panchayat*. New admission happens only with the permission of colony *panchayat* and house is given if and only if person is affected with leprosy. *Chota pradhan* of this colony shared that house is given after paying Rs 60,000 to *panchayat* but in very needy cases they do have some amount of flexibility. List of the same is submitted to state leprosy office (SLO).

Colony has its own set of strict rules and regulations as well. Strict disciplinary action is taken against those who bypass it. No man is allowed to enter in houses of widowed women. If any resident breaks rule like fighting in the colony, creating menace after getting drunk, gambling etc then a heavy penalty is levied upon those who are found guilty with no leniency for both men and women. *Ration pani* i.e. donation and charity material which comes to the colony, is stopped for residents who flaw the rule. In one more situation *ration-pani* is stopped to the concerned house- in a situation of inability to pay back loan. In such a case it is given to those households from where money is borrowed. But cooked food given in charity they can always collect.

Chota pradhan shared about one of such instances. He explained

> "*Yeh* ***Ma (aged 40, widow)*** *hai na iska ration pani abhi band hai. Pikar ghumti hai. Mana karne par bhi nahin manti. Bahut bola ki pati nahin hai tera, beti bhi jawan ho gayi hai. Kuch toh soch. Ghar par hi reh piker par nahin manati*" (R*ation-pani* of Ma is stopped by panchayat. She gets drunk and roams around in the colony. In spite of being told she does not listen. She is a widow and her daughter is also young but still no effect. We have asked her to remain indoors and drink but she still does not listen)

Another such instance was shared by wife of **Anj (aged 45),** one of colony residents affected with leprosy

> "*Hamara ration pani abhi nahin hai. Hum par karza hai woh kirane wali nahin uska lack rupay ka. Ussi ko saara daan ka saman chala jata hai har mahine. Samne walono ko pension ka paisa jata hai karza chukane mein. Hamara gujara bheekh mang kar hota hai*" (We do not get any *ration pani* since we have taken a

> loan from colony *kirana* shop. Al that comes from donation, our share goes to them till the time we repay back. Pension amount goes to people who stay in front. We survive by begging)

Thus from above two narratives it is very clearly evident that colony maintains its own optimum functioning with certain set of rules and regulations which all the residents abide with. In situations of violating the same strict action is taken by '*Panchayat*'. It is interesting to note two totally different kind of world systems existing which are in dire contrast with each other and located just next to each other. On one hand side there is Jeevan Deep Kushta Ashram and on the other hand side larger RK Puram slum and locality is there. Both of them are distinct in their own unique ways with certain characteristics. But existence of leprosy colony as 'stigmatized neighbourhood' gains prominence and accordingly their own small little world system is constituted.

A deeper analysis of life processes in colony reveals that patriarchy is deeply ingrained in its various hues and colours in this colony. For example, neither there are any women members in the *panchayat* nor they are allowed to participate in any of the meetings. If they have any concern it is told in advance to the *panchayat*. During entertainment time, women sit separate from men and chat while men too have a different group.

Thus, leprosy colonies including Jeevan Deep are a mini world of their own. It will be more appropriate to say that they are rather compelled to acquire this socially segregated way of living with some forms of give and take relationship(s) with the world outside. This distinction has been expressed by colony residents themselves by using words like *hamara samaj, hamare log, unka swasthya samaj* (our society, our people and their society, their healthy people) etc. Having learnt about the set up of a leprosy colony now it will be appropriate to understand and analyse social networks of people affected by leprosy who are the residents of these colonies.

4.2.3.1 SOCIAL NETWORKS OF PEOPLE AFFECTED WITH LEPROSY

One might question the need of understanding social networks of people affected with leprosy. It is essential to understand inter-linkages between health, illness and social network[52]. Concept of social network helps in understanding 'web of social relationships' which is detrimental in linking health with illness of people. It may comprise of a number of relationships people have as an individual and as a group,

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[52] Radley.A (1994; 176)

frequency of contacts and kind of groups of which individuals are part of. These relationships may either constitute a positive social support for people affected with leprosy or can have negative effects too.

In the context of current study, existing social networks and socialization of people affected with leprosy in Delhi are either with people of the same colony or with people from the same state residing in other colonies (Lajpat Nagar, Kasturibagh in Tahirpur). But they all represent together as a group when it is required in any meeting, delegation or protest etc. In their native place too, they do visit leprosy colony located in Bellary which has many of their known people. Sharing by **52 year old** research participant **De** illustrates the same

> "*Haan kabhi kabhi jate hain. Wahan ke log yahan rehte hain aur yahan ke log wahan bhi rehte hain. Meljol rakhte hain*" (Yes I do visit sometimes. People from there stay here and people from here stay there as well. We keep in touch)

In fact, marriages are also within the same or different colonies mostly among people from the same state. During fieldwork in the colony, two marriages were witnessed in RK Puram leprosy colony. In the first marriage, girl and boy were both residents of the same colony but their parent(s) had leprosy. While in second marriage, boy was from Bellary whose parents were leprosy affected and relatives of one family in RK Puram colony and the girl was from Lajpat Nagar colony with both the parents leprosy affected. Even during general interaction with colony residents, I found out the same pattern- they are seldom able to break this vicious cycle of spending entire life in the colony itself. Rationale behind doing so was embedded in the concerns of parents (leprosy affected) about their healthy children. It was shared that just the way they have been stigmatized all throughout and forced to live in a leprosy colony, similarly their children also face stigma because of leprosy affected parents. Neither people from *swasthya samaj* (healthy society) are willing to marry their children nor are they confident of marrying their children outside. There is no guarantee of security for them outside.

It is known that when people cooperate in social networks, social capital in form of support, self-esteem, identity and perceptions of control is produced[53]. This is exactly

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[53] Cattell (2002;1502)

the case in leprosy colonies as well. Within the colony, relationship between all is like one big family where relations are on the basis of common bodily characteristic-all of them are affected with leprosy. Stigmatized identity of 'a leper' is commonly shared by all people affected with leprosy residing in the colony. Note here, the word used is people in its plural sense rather than person in singular sense (as per the present norm in leprosy discourse). Upholding this spirit, narrative of **55 year old Go,** revealed

> "*Yahan sab parivar jaisa hai. Koi kisi ka khoon se bhai behen toh nahin hai yahan par haan sab kodi hai idhar. Sab jaat dharma ka log mil jul kar saath rehta hain. Bahar samaj mein toh kaise jana. Woh nahin leta humko. Humlog idhar hi rehna apne log mein*" (Here it's like a one big family. Nobody is related by blood but all are affected with leprosy. People from different caste and religions stay here in harmony with each other. How is it possible to go out and stay with *bahar samaj*? They do not accept us. We all stay here among out people.)

Communication and relationship with family members varies from person to person including the case of all research participants. They do go back to their native during festivals like Muharram (this is commonly celebrated by all colony residents irrespective of their religion) and on yearly vacation. Some are still in good contacts with their relatives in their native while for few others there is no contact of any kind. It is commonly found that people including research participants, who were supported by their relatives even at the time of affliction and diagnosis with leprosy, are still in good terms with them. While those who were ostracized and stigmatized by their own relatives, are either in no or in very minimal contact with them in the present times. There is a third situation as well wherein relationship is renewed to an extent with relatives with whom people affected with leprosy had lost contact while leaving because of being stigmatized by them. According to research participant **Sh, aged 40,**

> "*Kabhi kabhi jata hoon 3-4 dinon ke liye gaon mein bhai ko milne ke liye. Mein baat karne ke liye jate hain. Par kaam chalau hi hai. Hum rehte nahin hain wahan. Abhi na thoda sahi ho gaya hai toh jata hai wahan. Accha bolte hain ab. Kam ho gaya hai isko bimari aisa bolte hain. Log baat bhi karta hai. Bhai aur uski biwi ko pata hai ki hum yahan Delhi mein rehte hain. Nahin aata hai woh log yahan par. Pata hai unko mera ghar bare mein*" (Yes I do go sometimes for 3-4 days to my native place. I go to meet just for formality sake. We do not stay there.

> Now they are much better and talk well also. Since disease has also come down so people comment positively. My brother and his wife know about my stay in Delhi. But they do not visit us).

Another participant, **Hu aged 40**, shared

> "*Pehle gaon mein aisa tha. Abhi toh pura desh mein iss bimari ke bare mein alag alag system ho gaye hain-yeh bimari khane pine se nahin failata hai. Abhi toh leprosy ka kahani khatam. Abhi ghar par sab thik hai. Aas pados wala koi log aitraaz nahin karta hai ab. Hamara ek ki wajah se pehle sabko parehani hua tha par ab nahin hai. Abhi gaon mein bhi bimari zyada nahin hai par pehle tha. Ab log ghar chod bahar nahin ana. Aas pados mein ab pata bhi laga kushta rogi hai toh bhedbhaava nahin karna-sab pyar se rehna ab*" (It used to in the village earlier. Now it is known that this disease does not spread by touch, through food etc. Now everybody is alllright at home. Even neighbours do not object. Just because of me people had to face trouble earlier but now situations are different. Now in village, disease prevalence is not much. People do not have to leave their houses to come here).

Sh and Hu's narratives brings in an interesting dimension which was reiterated by others too. As per them, now there has been a decrease in intensity of the disease as compared to earlier days. Their stay in Delhi-a metropolitan has been with comparatively better living conditions which also give them certain respectable status back in their native places. They brought in an interesting dimension in relation with social experience of leprosy-differences in experiences on account of rural and urban place of residence. Commonly used sentence was "*Ab wahan jata hai na toh log izzat deta hai thodi. Thik se baat karta hai tum Delhi mein raho kar ke*" (Now whenever we go there people respect us. They talk well with us and say you stay in Delhi!).

Another aspect which was revealed during fieldwork was gifting or giving away things in surplus to the relatives in Karnataka. Colony residents save some amount of donation which comes to them and take it back home while visiting their native. Some of them even save money and give it to their relatives while they visit them. **65 year old** research participant **Fa** shared

> "*Hum jab ghar ko jate toh kuch lekar toh jana hota na rishtedaaron ke liye. Saal mein aye hain toh khali haath kaise. Yahan par jo kuch bhi milta hai daan ka ussi mein thoda bacha dena unko. Hum ko bhi zyada hi padta. Thoda unhe de diya*" (Whenever we visit our native then we must take something for our relatives. We visit them yearly so how can we go empty hand. Whatever donation we get here, we save a little from it and give it away to our relatives. For us also it is more).

Another participant **De aged 52** shared

> "*Mein yahan mang mang paisa jodti hoon. Jab Karnataka jati toh apni behen ko thoda paisa deti hoon. Lekar jati hoon yaha se*" (Whatever I get from begging in Delhi, I save a little from it. When I visit my sister in Karnataka I give her some amount).

During one of the visits, I observed **Ya aged 71** giving away nuts, blankets, clothes, pulses etc to his daughter when she visited him. According his daughter,

> "*Unke pass yeh sab zyada hi hai. Unko kaam mein nahin aaega toh mujhe de deti hai. Ghar par parivar hain unko kaam mein aa jata*" (He has all this in plenty and he does need it. He gives it all to me which comes to my family's use in Karnataka)

In Delhi across leprosy colonies, isolation has been observed from external neighbourhoods. Take the case of RK Puram Leprosy colony. This colony is a part of larger RK Puram Ambedkar slum but it is markedly distinctly located from the slum with a separate housing and boundary wall. Stigmatised reputation of 'a leprosy colony' has widespread and detrimental effects on inter-neighbourhood social networks. Display of stigma by neighbourhood locales has created conditions of personal and group isolation exhibited by colony residents. There is a limited communication with negligible co-operation. This is reflected through narratives of research participants as well. **50 year old Me** shared

> "*Baat karne ko toh thoda bahut karte hain. Wahan ki kuch auratein pani lene ko aati hai yahan aur aata daal chawal kharid le jati hai. Par hum zyada mel jol nahin rakhna. Uthna baithna waise kam hai. Woh hamare ghar nahin ana aur hum bhi nahin jana. Kodi colony log bolkar lete*" (Like that we so speak sometimes but do not mingle with them much. Women from there come here to

> fill water and buy pulses, flour, and rice from us. Neither they visit us nor do we visit them. They say we are from leprosy colony).

65 year old participant **Fa** also expressed the same

> "*Humko toh bas yehi colony pata hai. Dusare jagah hum nahin ghumte. Yahan hi rehte na. Kabhi kaam pada toh aaenge ya jaaenge. Bellary mein bhi apna colony hain. Wahan par ana jana aur wahan ka log idhar ana jana*" (I know about only this colony. I do not go to other places. Here only I stay. If there is some work then only I go out. In Bellary also we have our colony. When I go there I visit them and people from there visit us).

Another set of sharing was made by some women of Ambedkar slum when a visit them was made during one of the fieldwork days. This slum is located just outside the back gate of RK Puram Leprosy colony. Women unanimously expressed

> "*Woh toh kodi log hai. Hum unse milna julna kyon rakhna. Woh bhi nahin rakhte hain. Apne mein hi hain woh log. Sarkar toh unko bijli, pani, ghar sab muft mein diya hai. Hum toh yahan unse bhi pehle se reh rahe hain par abhi tak kuch nahin hai. Bijli ka bhi meter hai yahan. Yahin nale kinare hum log rehte hain. Unke yahan se pani bhar late hain kabhi kabhi*" (They are lepers. Neither we mingle with them nor do they. They are restricted upto themselves. Government has given free electricity, water, proper housing to them. On the contrary, we have nothing in spite of staying here for much longer duration. For electricity we have meters, and stay next to this *nala.* We do feel water from the colony at times).

It will be apt to comment that people affected with leprosy residing in RK Puram leprosy colony and other colonies in Delhi have a particular kind of social network 'within people of the same kind'. They do share give and take kind of relationship for mutual profits with external neighbourhood but not to extent of mingling with each other. There is a clearly marked distinction between 'them vs us'. Constitution of these 'stigmatized neighbourhoods' has been historical where people affected with leprosy are pushed to periphery of the cities and even a particular locality. In urban areas, one will find geographical location of these colonies either in outermost area of the city towards the periphery or next to some *nala* or dumping place or on some unauthorized land[54]. Location of leprosy colonies in Delhi has been of course one of the most privileged one's. Moreover, with urbanization boundaries of the city are also expanding. So localities like RK Puram which were earlier at the peripheral region of Delhi are now one of the posh localities in Delhi. As revealed from sharing's by older participants about origins of this colony, initially when they had come here there was nothing except for few offices etc. There were all scattered in nearby *sarai's* and came together as a group in this locality which later took the shape of a leprosy colony. In terms of relationship shared with relatives, it varies from person to person. But certainly, they have well defined communication patterns with people affected with leprosy residing in leprosy colony back home (in Bellary). Some have married their healthy children in leprosy colony of Bellary. On certain important occasions like festivals, elections they visit Karnataka and meet their relatives as well.

Thus, it is important to realise a very distinct social constitution and composition of the social network which people affected with leprosy share. It certainly plays a very crucial role in social experience of the disease too. No doubt, the very same stigma which eroded their social networks in their natives brought all of them together as one large community and lead to creation of newer social networks amongst themselves. At this juncture, it will be apt to write that stigmatizing health conditions like leprosy can certainly act as a motivation and a binding force in maintaining strong social networks among people affected, but the motivation to avoid social rejection for a stigmatized condition in the world outside may be even stronger in bringing people together.[55]

4.2.4 BEGGING AND LEPROSY: UNDERSTANDING FACTORS RESPONSIBLE AND PROCESSES INVOLVED

There are two ways of looking at an act of begging, here in the context of leprosy. One involves, victim blaming where beggars are seen as those who want easy money with an unwillingness to work. This kind of attitude is widely encountered in relation with people who beg including those who are affected with leprosy (both with Grade 1 and Grade 2 disability). Another viewpoint, involves a deeper scrutiny of begging act and context in which it is ingrained. There are certain situations and factors responsible within which an individual or groups of people as a whole are compelled to beg against

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[54] This was shared very explicitly by state leprosy officer (SLO) of Delhi and is confirmed with field observations too.

[55] Smith RA & Baker M, year unknown

their choice and human dignity. It is necessary to pay attention to causal and consequential correlation between begging, leprosy, stigma, poverty, social exclusion and inadequate access to basic essential services. This is discussed in detail in Chapter 7.

Second viewpoint stated above is clearly reflected from the field situations. Initially, begging arose within situations of acute poverty and destitution in the lives of people affected with leprosy. Overtime, situations have remained largely unaltered and begging has become only means of accomplishing daily survival needs by people affected with leprosy. They are out of any kind of social security net or welfare measures of the state and without any sustainable means of earning. Begging has become a survival strategy which is strongly driven by forced choice under certain circumstances. It is important to note different categories of people affected with leprosy among those who beg. One group comprises of those who are very old, disabled and unable to do any kind of work. Second group comprises of those who are comparatively in younger age group but unable to beg on account of disability, ulceration or denied any kind of work. There is a third category of people also who look healthier and able-bodied but suffer from Grade 1 disability on account of leprosy. Common thread among all of them is either total inability to work or denial of employment because of affliction with leprosy.

Among research participants, all of them beg except for **Hu** who used to beg in the past but now works with MCD as a sweeper. '*Mangne jate hain*' (we go to beg) was a common phrase used in the colony including research participants. They go to beg either alone or in pairs using hand cart. Reason for using handcart in pairs was explained by **Hu, aged 40**

> "*Gadi use karne se kya fayda hota na ki police kam pakdta. Chod deta hai lachar bolkar. Unko bhi andar rakhne ko nahin hota na. Aise jaenge toh mangne ko toh Police pakad leti aur band kar deti. Phir paisa de chutna*" (When cart is used to beg, police does not catch us. Thinking that they are disabled, police spares them. If they go like that only to beg, police will catch. Then one has to pay money to get them released).

Another participant, **De aged 52** shared

> "*Mein mangne ko akele jati hoon. Din mein do baar jati hoon- subah mein 6baje jakar 11 baje wapis. Phir khana kha kar safai kar 2 baje phir jati hoon. 5 baje tak phir wapis aa jati hoon. Akele jane se kamai zyada ho jati hai. Do log sath jane mein adha adha baant lena hota hai*" (I go to beg alone twice in a day- morning 6am to 11 am and afternoon 2pm to 5pm. If I go alone I can earn more else one has to share if they go in pairs)

From this amount, **De** saves a little and gives to her sister whenever she visits her in Karnataka. She also receives a monthly pension of Rs 1800 from Delhi government but this is not sufficient to run expenses in a big city like Delhi.

Disabled body and diseased condition becomes a big impediment in earning a living through begging for people like **MuS, aged 58.** He is not only very old but also suffers from neuritis and lagophthalmous eyes as physiological manifestations of leprosy. He cannot walk properly because of ulcers and pain in legs. He is unable to see clearly and because of lack of money cannot get operated either. He expressed

> "*Bahut kathinai hai. Pension 1800 rupay mahine ka hai par kabhi ata aur kabhi nahin. Kya karna ab. Mangne ko jana roj kamane ke liye. Kyonki dono aankhon se dikhata nahin thik se aur chalna bhi mushkil. Isiliye saath mein mangne ko jana roj subah mein gadi mein baith kar. Dupahar mein nahin jana*" (It's very difficult. I get monthly pension of Rs 1800 but not very regularly. What to do then? I go to beg daily to earn a little. I cannot see properly with both eyes and walking is also difficult. This is why I go in pairs to beg. I go in the morning and come back by 11. I do not go to beg in afternoon).

As mentioned above, begging is a situational outcome and a forced choice made under certain circumstances. Beggary needs to be viewed as one of the social consequences of leprosy where in people who beg are dehabilitated from normal social processes and relations. This immensely impacts conceptualization of their dignity as well which is discussed in Chapter 6. Begging creates an identity of a 'disabled-bodied heinious leprous beggar' in the lives of people affected with leprosy. As evident from field situations, none of the people used to beg in their native places and till the time leprosy afflicted them. Begging was started in the realm of no other means to meet daily essential needs and anonymously away from their native places. Stigma is conjured up not only with their affliction with the disease but also with their very act of 'begging'.

They are perceived as public nuisance and caught by police as per anti begging act[56]. This was reiterated in the field by research participants as well as by other colony residents affected with leprosy. As shared by **71 year old Ya**

> "*Yahan par kya kaam hai. Sirf bheekh mangne ka hai dusara juch nahin. Kuch naukari wagarah karne ko nahin hota hai humse. Kaam nahin ho pata hai. Kiase karenge kya karenge toh mangna toh padta hi hai. Nazar bhi ab kam hai. Sunday chod roj jana mangne subah aur shyam*" (There is no work here except to beg. Iam not able to do any job etc. Iam unable to work. How to do, what to do? I have to beg. Eyesight is also weak now. I go to beg every day in the morning and afternoon except for Sunday).

Another participant **Hu, aged 40** expressed

> "*Mangna toh kisko accha lagta? Hum toh bheekh mangta tha par bhi humko sharam lagta tha kabhi kabhi. Kab tak bheekh mangne ka? Yahan aane baad se rishtedaar door ho gaye. Unhe gaon mein chodkar idhar aya na. Paisa idhar baithe baithe kahan se ana. Thoda din isiliye begging kiya phir uske baad Madam (Sushma Swaraj) ne thoda madad kiya humko aur naukri ho gaya phir*" (Who likes to beg? I used to beg but felt shame and embarrassment in doing the same. For how long one can beg? After coming here all my relatives distanced themselves. I left them in the village and came here. By sitting here without work how money would have come? Because of this I did begging for some days and later got some work with the help of Sushma Swaraj).

Narrative presented above recapitulates entire crux of begging by people affected with leprosy.

An element of helplessness and availability of no other options to fulfil basic daily needs was reflected in narratives/sharings of all the research participants. **Sh aged 40** expressed

> "*Kamane ke liye kya!! Idhar udhar dani log rehta hai. Koi deta aur koi nahin dete. Kuch mile toh nahin mile toh aise hai. Koi koi khana deta hai. Mangne ke*

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[56] This is a historically ingrained notion where even during British times in India, people affected with leprosy begging on the streets were believed to be a cause of public nuisance and picked up by police as per law.

> *liye jate hain kabhi kabhi. Roz nahin jate. Biwi nahin mangti woh ghar kaam karti hai. Gaon chodna baad mangna shuru kar diya. Bellary mein log aitraaz karta tha mangne par, par yahan Delhi mein nahin aisa. Amdani bhi thoda zyada hota yahan. Din ka 50-100 milta kabhi kabhi. Koi khana bhi de deta. Wahan aisa nahi hata. Roz thoda kamai ho jata*" (There are donors here and there. Some give and some do not give. Some give food also. I go to beg sometimes but not daily. My wife does not go to beg. She does housemaid work. I started begging after leaving my village. In Bellary, people used to object to begging but here in Delhi situations are different. Nobody objects. Earning is also little more as compared to what I could earn in Bellary. Here I can earn up to Rs 50-100 at times. Some give food also).

Fa, aged 65 is a widow and stays in Delhi with her daughter, son-in-law and three grand-children's. For her begging even at this old age is nothing more than a total compulsion and a choice made in complete desperation to somehow survive and contribute in fulfilling essential needs of her extended family. She had started to beg for the first time in Bellary after her adopting her daughter. Family needs had increased with no means of earning. She shared about her difficulties in begging as a woman and because of the disease,

> "*Kya bas yahi kaam hai bheekh mangne ka! Pehle bhi Bellary mein rehte time idhar udhar jate the chote chote khede mein. Hyderbad hua, Hubli hua. Ek hafta 15 roj mein jakar aate the mangne ke liye. Rs 200-300 hafta ka ho jata tha. Mein aur pati dono milkar jate the. Par jab bacchii aa gayi na tab iska thoda bada hone mein rehti thi. Bacchi aane ke baad hi pehli baar mangna shuru kiya. Pehle nahin karti thi. Pehle jab baap ghar hati tab toh kabhi nahin manga. Aj ka time mein kya na- paisa jama kar beti ka shaadi kiya. Phir teen bacche hue. Ab unka padai likhai sab dekhna hai. Chote hain. Private mein padte hain. Accha padai mil jae. Maang kar thoda paisa bach jana. Pension ka paisa se bacchon ki padai mein thoda sahara lagta. Woh gujarne (pati) se phir mein baithe rehne se toh nahin hoega na. pension band ho gaya. Kharcha ko muskil hua. Private mein toh damaad ka ek din kaam rahe ek din nahin. Baccha kahan jaenge. Mein maang kar Rs 100-150 mila. Aise hi ghar toh chalana padta na. Dudh, sabji, tel, kapda sab toh karna padta na. Mangne mein koi do gali bhi sonata. Accha hua toh kuch nahin. Police bhi lachaar bol kabhi chod deti*" (Here only work is begging.

> Earlier in Bellary, we used to go here and there for begging like Hyderbad, Hubli etc for 15 dyas or so. We could earn Rs 200-300 a week. Me and my husband both used to beg. After we had our daughter, I used to be at home. I started to beg for the first time after our daughter since our needs also increased. When I was in my parental house I did not beg. In current times, I married my daughter after saving money. She had three children. Now there studies have to be looked after. They are still small. They all study in Private since good education is available. By begging I can earn and save a little extra. With my pension some additional support is provided to my grandchildren. After my husbnad's death situation were stressful. His pension stopped coming. It was difficult to manage expenses. My son-in-law works in private where work is very sporadic. House expenses have to be run somehow. While begging some verbally abuse me while few others say nothing. Police spares me sometimes saying that Iam disabled).

Narrative of **Fa** presented above gives an account of how she actually started begging, what compelled her to get into begging during earlier days, her life today in Delhi and factors which still keep her engaged with begging act in spite of old age and complications because of the disease. This is not a situation just alone with **Fa** but there are many others in the colony who have a similar life story to share.

Another aspect to be noted in relation with begging by people affected with leprosy is the 'site of begging'. Different sites are chosen by different people as per individual preference. There is an inbuilt understanding that none of them from the colony will hinder begging by their other fellow mates. Among the research participants most beg on the streets, close-by red light signals and few like **Sh, Me** go to residential areas.

Thus, it is important to understand begging by people affected with leprosy in a context with particular compulsive situations. There are people like **Hu** who have quit begging in the presence of another option to earn a living. Narratives of other participants also reveal that begging is used as a daily survival means to meet basic needs in an absence of other options to earn. These are the people who are out of the reach of social security measures of the welfare state. Begging shapes social experiences of people affected in a distinct manner adding to an existing identity of 'a leper'. This certainly impacts their dignity to a great extent. Delhi not only provides them with anonymity of begging but also more earning. It is also accompanied with charity and donation which happens more often in Delhi. Infact, many of these people who are siphoned off into begging are either those who never underwent any treatment or those who are dehabiliated even after cure with withering away of all socio-economic support mechanisms.

CHAPTER 5: HEALTH EXPERIENCES OF PEOPLE AFFECTED WITH LEPROSY

Taking an account of overall health experiences (including treatment aspect) of people affected with leprosy is important for two reasons. Firstly, to understand the situations and factors which played role in the past in determining their health outcomes. And secondly, to understand why their health conditions are the way it exists in present times. One of the ways to understand the same is by documenting illness narratives of people affected with leprosy which is subsequently dealt with in the present chapter.

Interface between people affected with leprosy and health service system is not determined by their mere affliction with the disease but it is also shaped by socio-economic and cultural factors. It was very appropriately articulated[57] that 'health behaviour' of populations is largely influenced and impacted by availability, accessibility and affordability of health institutions and cultural meanings attributed to health problems (in this case leprosy). And this health behaviour is in turn largely impacted by the larger 'health culture' of populations which is influenced by an interplay of poverty, caste, class, religion, gender, power, leadership and decision making and other social determinants. Role of caste, class, religion and gender are very clearly evident from the field in terms of influencing health status of people. Gender differentials in treatment seeking behaviour have been crucial in understanding differential health outcomes among men and women affected with leprosy.

Entire health experience of people affected with leprosy (both in Karnataka and Delhi) can be understood in four stages as depicted below (see the figure 5). Health experiences should be seen as a continuum across life time wherein there is a cascade of life events which are all inter-linked. These life events are impacted by various factors like health service system, economic situations, social stratification and nature of

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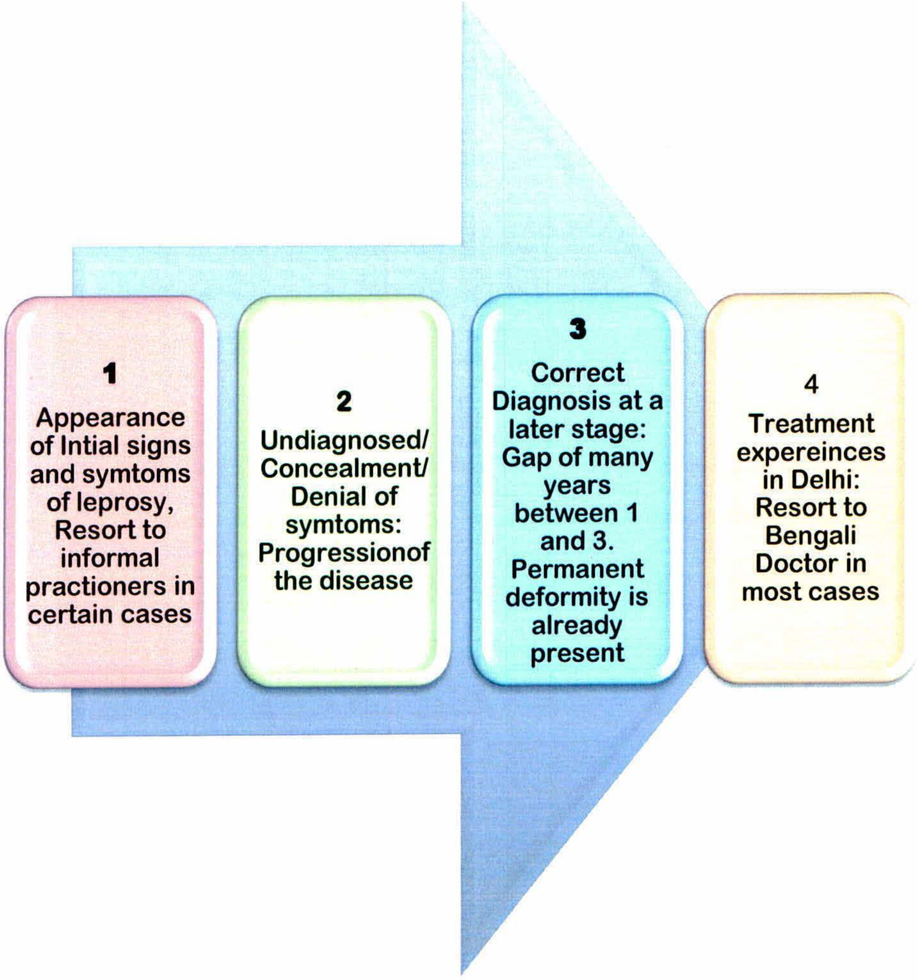
[57] Banerji, D (1982)

socialization, cultural norms and beliefs. It is also important to understand how people resort to various kinds of treatment and deal with leprosy and other health complications in their daily lives. One must also factor in negative social experiences of leprosy in the form of stigma, discrimination in various ways, social exclusion from socio-economic-political-cultural processes, various forms of indignities resulting in intense humiliation and completely disrupting notion about oneself. These experiences cuts across caste, class, religion and gender as evident from the field.

Figure 5 Entire health experience of people affected with leprosy (both in Karnataka and Delhi)



5.1 DIAGNOSIS OF LEPROSY: FACTORS INVOLVED AND SHAPING OF TREATMENT EXPERIENCE

Delay in correct diagnosis and treatment of leprosy has emerged as an important domain in shaping of overall treatment experience of people affected with leprosy. As evident from the field, delay in initiating treatment has been a major reason for severe forms of disability and disfigurement. In certain cases, by the time treatment was started it was already too late. Delay has been chiefly because of three reasons: unawareness, denial or concealment.

Narrative of **40 year old Hu** reflects an element of unawareness along with denial which lead to delay and further worsening of his disease. There were attempts to herbally cure him as suggested by villagers. He first sought treatment in Missionaries of Charity (MC) run hospital in Bellary and later he was referred to Bellary government hospital for a year because of the lack of facilities in MC run hospital. He shared

> "*Mein 15 saal ka tha jab leprosy aane laga mujhe. Pehle safed chatta aya body par. Mein 10th standard mein tha tab. Hamara gaon na bilkul chota hai. Woh patch aane baad gaon mein log socha ki yeh toh bhagwan ka hai yeh hai woh hai. Uske baad log humko kya kar diye na – neem ka patta khilana shuru kar diye. Uska juice wagarah bana kar dete aur haath pairon par lagate. Par bhi bimari phailata raha. Gaon mein ek Christian father the woh bole mera maa-baap ko ki patta khane se ladka barbaad ho jaega. Ise kushta rog hai jo bhagwan ka kuch nahin hai. Iska sarkari ilaaz karao. MDT dawa free milti hai. Khane se bilkul nikut ho jaega. Woh khilwao. Mein tab 20 saal ka hata aur shaadi ho gaya mera. Haath pairon mein tab itna nahin hata. Baccha hone tak 5-6 saal mein bimari bhad gaya tha. Phir Bellary mein Missionary of charity (MC) Hospital mein 3 saal ilaaz chala mera. 30 ka umar mein negative certificate de diya mujhko. MC hospitam mein se ek saal Bellary hospital mein bhi rahan kyon ken a wahan sara facility nahin hota tab*" (I was 15 years old when I got afflicted with leprosy. I was in 10th standard that time. It first appeared as white spots over body. Our village is very small. After patches started to appear, people in the village thought that they are because of God. People attempted to cure me by giving neem leaves. Neem juice was applied on my wounds and limbs. But still disease kept spreading. There was one Christian priest in our village who asked my parent to stop treating with neem leaves. Rather go to a hospital and get the right treatment. It is leprosy which is totally curable with MDT. I was 20 years old at that time and was married by then. My limbs were still not so severely affected. But after having kids within 5-6 years of marriage my disease progressed a lot. I was first admitted in MC run hospital and later referred to government hospital in Belllary.

> My treatment continued for three years. By the time I was 30 years old I received leprosy negative certificate).

An important aspect which needs mentioning here and which is highlighted by above narrative also is a belief about 'mythological causation of disease'. Leprosy was believed to be because of God often expressed as '*yeh toh bhagwan ka hai, bhagwan kaise kar diya haemin, bhagwan de diya bimari*' (It is because of God or How come God did this to us) and thus an element of 'sins and sinner' was also introduced. As shared by the participants, it was a popular belief that only those people get leprosy who have sinned against God. Once during one of the field visits to adjacent RK Puram slum people mentioned

> "*Woh toh paapi log hai. Isiliye bhagwan unko aisa kar diya. Hamein toh aisa kuch nahin hai. Unhi ko hai*" (They are sinners that is why God has given them this disease. We are perfectly healthy. How come we do not have and they only have it?)

In the case of women, situation was even worse where either no attention was paid to her suffering, signs/symptoms or deliberate attempts were made to conceal her disease because of the fear of social stigma and inability to find a partner for her marriage. Sharing by all four female research participants reveal the same. Sharing by **65 year old Fa** is illustrative of the same

> "*Yeh bimari sabse pehle 7 saal ke umar mein aaya tha par tab pata nahin kare. Kya hua kya hua aisa karke kuch pata nahin chala itna. Maa baap idhar udhar bataya bhi. Par pata nahin na khede mein. Yeh bimari bolkar haemin pata nahin chala. 6 saal baad 13 umar mein pata lag gaya bimari bare mein. Yeh bhi tab jab bimari bahut badne lag gaya. Bahut baad mein sarkari Doctor pass gaye toh bol diya ki Kushta ki bimari hai. Woh bol diye ki dawai chalao ab. Doctor bataye aur goli diye. Bole mahine ke mahine 30 goli khana- roj ki ek. DDS goli dete the. Choti si goli hati woh. Kabhi thodi bimari bhari toh Laplone diye the. Labmi wali thodi kali hati. Mahine mein woh 1-2 dete the. Woh khate khate thoda kam ho gaya. 6 mahina khaye hum. Kabhi ek time bhool kabhi ek time khao-khede mein toh aisa chalta rehta hai na. Khane se thoda kam ho gaya. Aage bada nahin. Doctor bhi band karne ko bol diye. Jab se hum kuch bhi nahin kar diye'* (I got afflicted with this disease when I was seven years old but that time I did not take

> any medicine. My parents took me here and there but we could not make out what it was exactly. After six years, when I was 13, disease was diagnosed. Disease had progressed a lot by that time. We went to government doctor very late and it was revealed that Iam suffering from leprosy. I was instructed to initiate treatment as soon as possible. I was given monthly 30 tablets of DDS. It was small tablet. When diseases progressed a little, I took laplone. It was a longer tablet and black coloured. I used to take it monthly once or twice. After taking medicines, disease was under controlled. If I forgot certain times I used to take it very next meeting- this way it continues in small villages! Once disease was under control, my medicines were stopped. Since then I too did not do anything).

Another female participant, **Me aged 55** shared

> "*Mein Bangalore mein hi rehti maa, bhai aur behen sath jab bimari ayi 15 saal umar mein. 10 varsh mein school jati tab thoda dana dana aya tha- thanda garam pata nahin chalata mujhe. Mein choti thi tab. 15 saal ke bahut din se meri maa ko pata nahin lag gaya goli leke. Woh pehla mera mummy ko pata nahin chala kaun sa goli, kidhar hospital mein- usko kuch pata nahin. Pada nahin na woh, papa mera nahin tha. Woh gadi aya tha machhar wala –malaria wala doctor ka. Woh na goli dene bola. Dekh ke bol diya ki yeh kushta rogi hai. Dikhana bola karke. Baad mein hai na mein goli khata. 20 saal ka hone par. Bahut ho gaya tha. 2 saal Dapsone goli khaya Bangalore mein Private hospital mein se. Mummy lekar gaya private mein. Shaadi 18 saal par hone baad 20 saal mein ek beta hone baad bimari bhad gaya aur phir private Doctor pass gaya. 2 saal goli khanya aur 6 mahina mein test hota. Pehla pati dubara chodne baad mein choti ladki le CL Hospital, Magdi road par Government hospital hai uska hostel mein chala gaya. 3 saal wahan rahi aur phir Delhi aa gaya*" (I used to stay in Bangalore with my mother, brother and sister. I was ten years old when some symptoms started appearing and I could not make out hot-cold by touch. I was 15 when I got afflicted with the disease. My mother did not know anything about medicines, treatments available and which hospital to go to for treatment. My mother was uneducated and my father had passed away. One van used to come with Malaria doctor. He saw me and said that I have leprosy. He asked me to initiate treatment and get medicines. Later I started medicines. I got married when I was 18 and by the time I was 20 disease had worsened. I had my first child by then. Then I went

> to the private Doctor. I took medication for two years and every six months some tests used to happen. My first husband left me for the second time. I shifted with my small daughter to hostel of CL Hospital at Magdi road in Bangalore. Then I came to Delhi?)

Both the narratives presented above clearly demonstrate the fact that there has been a considerable time lag between onset of first signs/symptoms and the time when the right treatment was actually sought. After finishing the treatment, none of them actually resorted to any kind of practitioner or healing system except for certain instances even after coming to Delhi. Bengali doctor in Delhi in nearby slum caters to most of their health related needs.

Factoring in the role played by stigma in determining and shaping of health outcomes of people affected with leprosy is also very essential. Internalized stigma has been significant in bodily dissociation experienced by people affected and resultant injuries through self-neglect[58]. Stigma associated with treatment seeking for leprosy has been one of the major impediments in seeking treatment from government hospitals where a separate counter or all together a ward existed for people affected with leprosy. And since it was a rural area[59], there was a fear of being recognized or located by other known people.

71 year old Ya expressed

> "*22 saal ka umar mein bimari aa gaya. Kheti karta tha mein. Dhire dhire bimari phailne laga. Logon ko bhi pata chal gaya. Koi nahin dekh raha tha. Sab log darta tha mujse. Hamara maa-bhai aur baap kuch nahin kar paya. Kya karein toh phir. Doctor pass dikhane mein sharam aata. Sabko logon ko pata chal jata ki haemin bimari hai. Bahut saal hum nahin gaye phir bimari bada toh sabon ko pata lag gaya*" (I was 22 year old when I got afflicted with the disease. I used to do farming. Slowly disease started spreading. People came to know about it one by one. Nobody was looking after me. All used to be frightened of me. My parents, brother- none of them were able to do anything. What to do then? I used

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[58] Barrett.R (2005)

[59] All the residents including research participants are migrants from Karnataka. Affliction with the disease started when they were residing in Karnataka. Later they migrated to Delhi.

> to feel embarrassed to go to the Doctor. For many years I did not visit any doctor. But as disease progressed, all came to know about it).

Moreover there have been problems on account of one's physical disability and inability to stand and wait for long hours especially in government settings. Nature of relationship shared with the doctor was also instrumental in influencing their choices. As expressed by **MuS, aged 58**,

> "*Ab bimari wajah chala nahin jata zyada. Dekhna mein bhi taklif hai. Operation nahin kara paya. Paisa kam. Mangna jata hota phir kaise jana. Baccha bhi chote hain. Woh Medical mein gaye toh duur padta. Itna hamse nahin hota. Lamba khada rehna. Number bhi aata. Doctor humko dekhta. Time kam deta. Dawai deta. Par koi koi chillata bhi. Bhedbhaava toh rehta. Humko accha nahin lagta. Dawai baad bhi bimari toh kam nahin ho gaya na*" (Now because of the disease Iam unable to walk. I can't even see properly. I do not have money to get it operated either. If I go for operation I won't be able to beg to run house. My children are also very young. Government hospital is far from here. One has to wait for long hours too. Iam not able to take so much of exertion now. When doctor examines, he gives less time also. Some even yell also. Discrimination is there. I do not like this. In spite of taking medicines there is not much bodily relief).

Above narrative brings in very important dimension in treatment experiences of people affected with leprosy- Behaviour of health practitioner and attitude towards their illness experience. Undoubtedly, Doctors are capable of treating their 'disease' bio-medically but their 'illness' which is more of an experience and suffering at an individual level, is yet untreated. People's expectation is that apart from only giving medicines mechanically; the doctor should also listen to them and give them time. As it is discussed in further section, this expectation of people has been of immense influence in determining their choices to resort to 'Bengali doctor'[60] who practices in nearby slum.

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[60] In local terminology 'Bengali doctor' term is used. He is not an authorized medical practitioner but practices allopathy or a mix of other systems of medicine based on his experience of working in a health setting or incoherent knowledge gained about certain medicines from here and there.

5.2 MEDICAL PLURALISM AND PATTERN OF RESORT

Health experience of people affected with leprosy has been across a continuum featuring a cascade of various inter-linked life events. This continuing kind of health experience, impacting in turn various domains of their life, is marked from a point when for the first time patch appeared on body. Among all the research participants, either no attention was paid to initial signs/symptoms or health advice was sought from informal health practitioners. This kind of inattention or denial or concealment by those affected is clearly evident from the field across the participants. Additionally, gender, caste, class based differentials also exist resulting into consequent disparities in health status. It was after many years, of initial onset of symptoms, that biomedical advice was sought and correct diagnosis was made. This happened at a time when symptoms actually progressed into an advanced stage of leprosy interrupting with daily life functions of people affected. Even among biomedical practitioners, advice was sought from a range of institutions which will be looked at subsequently. Certainly, people had very obvious reasons for the choice and order of resort to certain practitioners and systems of healing which had huge amount of cultural influence also.

As explained above, this aspect of diversity among health practitioners and consequent range of treatments resorted to has very clearly emerged from the field. People affected with leprosy had visited a range of formal and informal health practitioners in their native place (Karnataka) and in Delhi- herbalist (Vaidya/Ayurveda/Hakim), Bengali doctor, quack (*Jhaad phook wala*), biomedical practitioners etc. Among biomedical practitioners, people sought treatment in charitable, private hospitals/clinics, hospitals run by missionaries and voluntary organizations like The Leprosy Mission Trust (TLM) and government run hospitals. Self-cure and home-based cure was also evident in certain cases. People affected with leprosy often resorted to a range of treatments – herbal, quackery, allopathy which is illustrative of 'medical pluralism' in their treatment seeking experience. In certain cases, they were actually not aware about how to tackle the disease and few others deliberately decided to seek treatment through alternative practices. It should be noted that in this experience of treatment seeking there was a distinct pattern of resort with a clear hierarchy in order of preference. People made selected choices in a certain order in search of a cure or relief during an illness episode. They kept shuffling from one system of treatment to another in search of a quick relief and satisfaction. Costs incurred and relationship shared with the practitioner was also a significant consideration. Tendencies to first refer to certain kind of medicine systems or practitioners and then switch to others was clearly evident from the field.

In the case of one of the research participants **Sh, aged 40**, disease worsened mainly because of delay in getting the right treatment. Instead of addressing the symptoms with medicines available for leprosy right at a time when disease appeared for the first time, he was taken to different herbalists (*hakims or vaidyas*) to get cure for 'patches on his body' while he was in Karnataka. He visited shaman (*jhaad phook wala*) also but all in vain. He had no parents so his brother took him to all these people. **Sh** shared

> "*Mein 8-9 saal ka tha tab bimari aayi. Maa baap nahin the. Uss time par goli nahin liya. Mein idhar udhar dikhaya tha pehle par kuch nahin hua. Pehle jadi buti khaya tha ayurveda wala par use sahi nahin hoga. Sara bahar ho gaye woh. Thik nahin hua aur ungliyan mota mota ho gaye. Mera bhai lekar gaya tha wahan. 3 mahine ilaaz chala unka. Ghar par reh kar bhi ilaaz karaya. Baba (jhaad phook) ke pass bhi gaya par bimari aur ho gaya. Tab pata nahin na. Baad mein hum Bellary aa gaye. Wahan hospital mein bharati ho liya. 3 saal raha wahan akele. Mera jaisa aur bhi kafi sara log tha wahan. Kafi sare patient log the. Tab umar 14-15 saal thi. Par bhi bimari itna kam nahin hoga. Dawai leta raha. Phir hospital chod mein dost saath Delhi aa gaya. Pura 3 mahina laga. Phir aise Delhi mein bhi dikhaye Nirmal (Thangraj) mein, Kasturibagh mein (TLM). Wahan hospital hai na. Yahan akar goli pura kha liya aur nikut ho gaya ekdum. Hind kust nivaran sangha wala bhi goli deta. Yahan ek saal goli kha liya. DDS Lamphine ka goli kha liya. Uss time kuch hua raha toh Nirmal ya Nandnagri Hospital (TLM) mein bharati ho jate. Pairon mein zakh hona par Nirmal jate woh Sister logon ka hospital mein. Par ab nahin jata. Zyada hua toh Bengali Doctor hai pass mein. Hafte mein ek baar Safdurjung se gadi ata hai. Goli aur malham patti dekar jata woh. Goli woh khaasi bukhar ki hoti. Patti kam padta hai. Iltna zakhm aur 2 hi patti deta. Bahar se phir lena padta. Mangta aur toh na bolte hain*" (I was 8-9 years old when I got afflicted with this disease. My parents were not alive. That time I did not take any medicine. I went here and there for treatment but nothing happened. Initially I had taken some herbs but of no use. Disease got even worse and my fingers were thick and swollen. My brother had taken me there. I continued with that treatment for three months. I went to shaman also. But again of no use. That time I did not know. Later I came to Bellary.

> There I got admitted in the hospital. I was there for three years. There were many like me in the hospital. That time I was 14-15 years old. But still intensity of the disease did not come down. I left hospital and along with my one friend came to Delhi. It took me three months. Here I showed in Nirmal and TLM hospital. I took complete course of medicine here and was all right after that. Hind Kushta Nivaran Sangha gave me medicines for one year. If there used to anything complex I used to get admitted in TLM hospital or Nirmal hospital. But now I do not go. If something is really troublesome I go to Bengali doctor. He is close by also. One van comes from Safdurjung once a week. They give some medicines, bandages, and ointment. Number of bandages given is only two which are insufficient for us. I had to buy it from outside. If I ask for more they refuse).

Narrative presented above highlights a wide range of issues ranging from medical pluralism with a wide diversity in treatments, resort to practitioners in a certain pattern, resultant delay in treatment, significant role played by missionary and voluntary organization run hospitals in leprosy cure and care, inadequacy of government run health services for people affected with leprosy etc.

Go's (aged 55) narrative reflected about a similar kind of 'pattern of resort' which involved shuffling from one health institution to another in search of a better and effective treatment. She shared

> "*Mein Yadgir district se hoon. Karib 40 saal pehle bimari mujhe aya tha aur tab mein Raichur district hospital mein dikhane ko gayi hati. Pehle toh baba hata woh ilaaz kiya par bhi kuch nahin. Phir Hyderbad mein Kukadpalli gayi ek hospital mein apna pairr dikhane kyonki uss par kuch gir gaya tha aur haddi dikhane lagi thi. Wahan doctor ne surgery kar aisa kar diya (semi circle shape with all fingers amputated). Wahan mein 4 mahina rahi. Kyonki pair jal gaya tha isiliye operation kar diya doctor ne. Mujhe meri behen boli thi Hyderbad mein dikhane ko kyonki woh ek accha sarkari hospital tha. Pati bhi mere saath hathe. Khana accha nahin hota tha. Ekdum patli daal hoti. Accha nahin lagta tha. Hum khud hi bana lete hate kabhi bahar se. 3 goli diya hata doctor mujhe- lal, kali aur mehroon aur bola din mein 3 baar lene ko. Dawai saath doctor glucose bhi chadaya hata. Phir mein Yadgir wapis aa gayi*" (Iam from Yadgir distirct. Around 40 years back I got afflicted with this disease. There was a quack in my native who tried to treat me

> initially. Later, I visited Raichur hospital to show my feet and then to another hospital in Hyderabad. Something had fallen over my feet and it was bruised. Bone was also visible. Doctor did a surgery and corrected my feet. I stayed in hospital for four months along with my husband. My sister had asked me to go to Hyderabad for treatment since it is a good hospital. Food given in the hospital was not good. Daal was very watery. I did not like it. We used to either cook ourselves or buy from outside. Doctor had given three tablets to be taken thrice a day- red, black and mehroon. Later I returned back to Yadgir).

As revealed by **Go,** she never went for any medical treatment for leprosy which over time resulted in severe deformity because of repeated ulceration. She did seek advice from a quack initially but it was of no use. Her patches were visible over her body with a loss of sensation in limbs but still attention was not paid. On account of untreated wounds and ulcers, her foot was severely bruised and it was operated in Hyderabad resulting in amputation of her toes. Here the main trigger for her shift from one hospital to another was her dissatisfaction from services provided at Raichur hospital and advice given by her sister to come to Hyderabad[61]. Assurance about availability of better services and closeness of Hyderabad to her district motivated her to shift.

Participants like **Ya, aged 71**, brought to fore one hidden dimension of treatment experience: 'an element of desperation and choices made on account of it'. In the realm of inadequate government health services, costly private health care, inability of Bengali Doctor to treat certain ailments, people affected with leprosy resort to voluntary organizations and missionary run hospitals like TLM (Nandnagri) or Nirmal (Thangraj/ Sagar) hospital. According to them, comparatively these hospitals are still better in spite of the requirement to pay consultation or hospital charges. In Delhi, these hospitals are very far (North East Delhi, Shahdara) so it is not very easy to commute on a regular basis. **Ya shared**

> "*Bimari toh kya 22 saal par aa gaya tha. Sab chod yahan Delhi aa gaya biwi baccha sath. Kuch ilaaz nahin liya pehle par jab bimari bahut bhad gaya, ghaav bhad gaya tab Doctor pass gaye. Mujhe pehle maloom nahin tha. Logon ne Bellary jane ko bola tha. Mein Bellary mein Leprosy hospital mein admission kara liya aur wahan 3 saal raha. Deformity aur ghaav aa chukka tha tab tak.*

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[61] It takes three hours by road to reach Hyderbad from Yadgir.

> *Doctor ne bola kod rog sambhav hai. Wahan dava pani sab hua aur phir negative ho gaya. Yahan Delhi mein kuch chota mota bimari hua toh Bengali doctor pass jata. Safdurjung ka gadi bhi kabhi aya kabhi nahin. Sarkari mein humko jane ko nahin hota. Private mein kharcha bahut hota. Nirmal aur Nandnagri mein dikhata tha. Par woh bhi kuch nahin karta!! Sirf admit karta hai. Pehle woh acche the 90 ke time par. Thangraj bhi paise leta hai. Christians ka hai phir bhi 600-800 Rs lag jate hain. Bahar se sab lana dawai patti sab*" (I got afflicted with this disease when I was 22. I left everything and came here along with my family. Initially, I did not take any treatment. As a result disease progressed a lot. Before, I did not know anything. People asked me to go to Bellary. I stayed in Bellary hospital for three years. Deformity had already appeared by then. Doctor said that it is Leprosy. I took medicines there and I was leprosy negative after that. Here in Delhi, for any kind of small health complication I visit Bengali doctor. Van from Safdurjung comes sometimes but not very regularly. I do not like to get treated in government hospital. In private, expenses are more. I used to show in Nirmal and Nandnagri hospital. But they also don't do much. They only admit. Earlier during 1990's there were good. Thangraj charges money now. It is run by Christians but still expenses come to Rs 600-800. Medicines, bandages etc have to be purchased from outside).

Undoubtedly, narratives presented above shed light on a mix of variety of factors which determine and govern people's choices within certain circumstances. These factors can be categorized into four groups: socio-demographic (age, gender, caste, class, social networks and peer group, stigma, place of residence etc), cultural beliefs (notion of sins/karma of past life, punishment from God, a result of immorality etc), institutional aspects (cost of treatment, attitude of health service providers, staff availability, services in a particular health institution, distance etc) and experiences of people with health service system (perceived notion of effective treatment, side effects etc). Understanding a prior background of people is also important in order to understand their treatment experiences in totality. It will be wrong to say or even assume that 'a particular experience of people affected with leprosy has been because of a particular reason'. There are inter-linkages which one needs to understand.

5.3 TREATMENT EXPERIENCE IN KARNATAKA AND DELHI: UNDERSTANDING THE TRAJECTORIES

While in Karnataka, most of the people who were affected with leprosy sought treatment either in Bellary leprosy hospital or CL Hospital, Magdi road, Bangalore or MC run hospital in Bellary. Christian philosophy of benevolence, acceptance and love towards people affected with leprosy attracted more and more of them both in Karnataka and in Delhi (there are two Christian health institutions in Delhi catering to health needs of people affected with leprosy: Nandnagri and Nirmal Hospital, Shahdara).

In Delhi, majority of them sought treatment from 'Bengali doctor' located in adjacent RK Puram slum. Reasons for the widespread popularity of Bengali doctor among people are many like his complete acceptance of people affected with leprosy and non stigmatizing attitude, low cost of treatment, close distance, efficaciousness of the treatment given by him and above all strong trust of people in him. When cases are beyond his control, he refers them outside. People from the colony also resort to Asha Polyclinic run by Maitryee Mission (NGO) which is located just outside the colony. A user fee of Rs 10 is charged from them. People have to pay for all additional costs like diagnostic tests, medicines etc. They also go to private clinics in surrounding areas in cases of acute emergency. In more complex situations, people resort to treatment in TLM run Nandnagri hospital or Missionaries of Charity run Thangraj (Sagar/Nirmal) hospital in Shahdara, North east Delhi. A basic minimum fee is charged and in-patient facility is also available. But since these two hospitals are quite far so people affected do not resort to them easily. One of the participant, **Me aged 50** shared

> "*Bahut door ho jata hai. Ana jana itna hota nahin bimari wajah se. Bahut hi kuch hua toh hi jana. Ana jana mein kharcha bhi toh lagta na phir. Auto se jana hota*" (It's very far. Because of the disease I cannot travel much. If something is really serious then only I visit them. Moreover, travel cost is also high. I go by an auto).

Interestingly, government hospitals like Safdurjung and AIIMS which are just 5-6 kilometres away from RK Puram leprosy colony are the last resort for treatment seeking by people affected with leprosy. Reasons cited for this choice were many like waiting period and queue is really long, inability to travel alone, attitude and behaviour of health staff and other people towards them, inability to move much because of the complications associated with leprosy. Most important reason which was cited was 'wage losses'. According to **Fa aged 65**

> "*Sarkari hospital- Safdurjung aur Medical mein kya na bahut bheed hota. Lamba line lagta. Doctor bolta kal aao parson aao. Number nahin lagta. Hum bimari wala. Itna nahin hota humse roj roj. Phir ek din jana matlab pura din ka mangna nahin. Hum toh roj kamaye roj khane wale admi hate. Log bhi wahan thik se baat nahin karta. Ab umar bhi ho gaya na. Itna uppar niche nahin hota. Kya karna idhar pass mein hi Bengali Doctor ko dikha lena. Woh accha illaz karta. Injection lagata aur safed goli deta. Sab thik*" (Goverment hospitals ike Safdurjung and AIIMS are very crowded. Its take a long time to get one's turn there. Queue is also very long. We are diseased. We are not able to cope with so much of stress everyday. And an entire day's wage is also sacrificed if we go to the hospital. We survive on our daily earnings from begging. People also do not behave well in government hospital. Now I have become old also. Iam unable to do much of up and down. What to do then? I go to this Bengali doctor who is close by only. He treats well. He gives an injection and white tablets. Everything is all right).

It is interesting to note in **Fa and Go** (see section 5.2) narratives presented above – a reference to injection, white tablets, glucose and colourful tablets. This kind of lay interpretation to allopathic treatment was expressed even by other participants. People's imagination associated with 'glucose and injection' as a hallmark to good treatment is worth noting. An understanding about medicines existed based on recognition through their colour rather than their effect and use. **Fa** repeatedly used to mention '*dard ke liye mein woh hare patte ki goli leti dukaan se*' (for pain I buy green colour tablet from the shop). Another participant **MuS aged 58** shared similar descriptions about medicines. He said '*Woh doctor pehle diya karta na- lal pate ki safed goli. Woh dukaan par se le leta. Baa baar kya jana*' (Earlier doctor used to give white tablets in red wrapper. I get that only from the shop. Why to go again and again?). This kind of behaviour is clearly illustrative of self-cure based on treatment given in the past by purchasing certain medicines over the counter. They recognize those medicines based on their colour, size, price and design of the wrapper.

5.4 NATURE OF RELATIONSHIP BETWEEN HEALTH PRACTITIONER AND PEOPLE AFFECTED WITH LEPROSY

Doctor-patient relationship in health institutions was an important determinant about people's continuation of treatment and treatment seeking behaviour for future. Experience shared by others also contributed in shaping of one's perceptions about health care services especially in government settings. Trust in a particular system of treatment and on practitioners, attitude, behaviour and sensitivity largely impacted access to and utilization of health services by people affected with leprosy both in private and government settings. Existing inequity in healthcare and commercialization of healthcare services in terms of escalating costs and purchase of services, aggravated existing condition for people affected both in Delhi and Karnataka.

As evident from previous section on treatment experiences of people affected with leprosy in Karnataka and Delhi, most of the people in the colony including research participants preferred visiting Bengali doctor over any other practitioner. Major reasons which were cited by people were 'his non-discriminatory attitude with complete acceptance, trust in him and his treatment, his sympathetic understanding and patient listening about our conditions'.

Narrative of **52 year old De** is self-explanatory. It not only explains about choice of Bengali doctor but also brings in problems associated with government and private health services.

> "*Woh Bengali doctor bahut sahi se dekhta. Accha hai woh. Bhedbaahva nahin karta. Chukar pyar se dekhta. Uska dawai bhi jaldi arram deti. Paise bhi hamra sthithi dekh leta hai nahin toh agla baar jane deo. 20-30 rupay hi leta. Yahan se sab log ussi pass dikahata hai. Pass mein bhi hai. Time par aata aur baiththa hai. Sarkari jaisa nahin. Sarkari mein number lagao. Ab aao kal aao karta. Thik se dekhta bhi nahin. Kabhi kabhi chillata aur. Humko sahi nahin lagta wahan. Private mein thik se dekhta par paisa bahut lagta. Hum garib aadmi mang kar din chalata. Itna kahan se lana? Thangraj bahut door hota. Zarurat hone par jate wahan par bhi*" (Bengali doctor treats well. He is good. He does not discriminate rather treats us with love and care. His medicines also bring in quick relief. If we cannot pay he does not hurry up. Rather he takes whenever we can pay him. He charges only Rs 20-30. Most people from here go to him. He is close by also. He

> comes on time and does not make us wait in long queue. He is not like government hospital where one has to wait for long. In government, doctor does not even treat well. Sometimes shouts at us also. We do not like this. Private is all right but charges more. We are poor people and depend on daily begging. How can we pay so much in private? Thangaraj is far from here but we go if required).

This narrative is not just representative of De's voice alone. But many others from the colony including all the research participants.

5.4 BIOMEDICINE AND LEPROSY: CHALLENGES POSED AND CONSEQUENT SHAPING OF TREATMENT EXPERIENCE

Dominance of biomedical notion of health and consequent emphasis on cure and treatment through medicines (earlier Dapsone and now Multi Drug Therapy MDT) has sidelined the need for overall holistic care and treatment of people affected with leprosy. Undoubtedly, people affected were rendered medically non-infectious after successful completion of MDT course but lifelong manifestations of leprosy are seldom taken care of. Limbs are anaesthetic for life with repeated instances of ulceration and increased chances of deformity, neuritis, lagophthalmous eyes etc persists even after complete treatment with MDT. Question which arises here is what after cure? Thus, the notion of 'biomedical cure with MDT (earlier Dapsone therapy) needs a deeper scrutiny because it does not remove lifelong complications and vulnerabilities to further damage. This emphasis on biomedical cure also affected treatment experiences of people affected. Their illness experience, side effects of MDT onto their bodies were not paid much attention in the realm of ongoing treatment with MDT. Even after 'medically non-infectious status' they were still feared by people and identity of a 'leper' was conjured up with their existence for entire life.

One of the participants, **Sh aged 40**, expressed

> *"Pehle toh mujhe pata nahin tha. Baad mein Bellary hospital mein ilaaz shuru kiya. Sarkari tha. 3 saal tha wahan par. Yahan par nas marta tha aise aise. Bahut rota tha. Goli khata tha par bhi bimari zyada ho gaya. Yahan yahan aise ho gaya (showed his hand and feet). Goli ki vajah se toh bimari bahut zyada ho gaya. Bahut positive aya tha uss samay par toh. Delhi akar ilaaz kiya ek saal. Negative ho gaya phir. Par bhi abhi ghaav hota hai. Pairon mein aise aise khichata hai (expressed with his hands). Diabetes aur BP zyada ka bhi bimari hai. 10 saal ho*

> *gaya hai. Negative hona baad bhi hum kodi hai na. Goli toh negative kar diya par bimari toh abhi hai*" (Earlier I did not know about the disease. Later I came to Bellary hospital for treatment. It was a government hospital. I was there for three years. Nerves used to ache like this (explained with his hands). I used to cry a lot because of pain. I took medicine but still disease progressed. It was like this on my hands and feet. I came to Delhi and took treatment for a year. I was given leprosy negative. But still I get wounds because of ulceration. My nerves ache in my both the legs. Since last ten years I suffer from Diabetes and high BP also. In spite of leprosy negative Iam still a leper. Medicine made me leprosy negative but disease is still there).

This narrative is illustrative of repercussions of high emphasis on cure by MDT but total negligence of care after cure component. Intervention with medical treatment at a right time is certainly important for improving their lives but it is not adequate in itself. People undertaking treatment for leprosy do face side effects because of MDT. These complaints are often unaddressed by health professionals as shared by the participants. *Disease* is certainly cured bio-medically by the doctor but '*illness experiences*' shared by people affected with leprosy are often ignored or negated. These are based on people's own objective experiential understanding about changes in bodily states and in physiological capacities, while doctor makes a diagnosis of the disease, here leprosy, based on certain pre-defined symptoms.

This kind of bio-medicalized emphasis is visible even in health communication material for leprosy where a fear psychosis is created based on certain bio-medical manifestations of the disease in an absence of treatment and a stress is laid on taking MDT to avoid the same. It is important to reflect here that the publicity about MDT has also impacted in increasing stigma attached with lives of people affected with leprosy in very covert ways. Recognition and addressal of the same is very much crucial. People in the field including research participants univocally voiced

> "*Woh parcha wala ata hai aur dawai leo bolta hai. Sarkar bhi khub prachar kar diya leprosy ka kahani khatam karne ko. Sarkar ka bhi parcha dekho toh yehi bolta hai. Kushta rog ki bimari ke lakshan de dawai MDT lene ko likha hota hai. Likha rahega ki MDT lene se kushta ka jivanu khatam ho jaega aur leprosy thik hoga. Par hum toh MDT liya phir bhi nahin khatam hua na*" (Pamphlets about

> leprosy speak about taking medicines. Government also publicizes a lot to eliminate leprosy. Government pamphlets also emphasise of taking MDT. Symptoms of leprosy are written with an instruction to start taking MDT in order to cure leprosy and kill the bacteria. But we took MDT but still leprosy is not cured among us).

Thus, biomedicine has only distinguished people's disease from their illness. MDT has certainly stopped bacterial growth rendering them non-infectious. But on a personal level, people affected continue to experience illness all through their lives which is seldom addressed by bio-medical practitioners. This kind of emphasis on leprosy cure and treatment just with medicine has not reduced apathy of people affected. But certainly it has enabled the state to bring down prevalence rate of leprosy (less than 1 per 10,000 populations: Current rate is 0.85) and declare leprosy as eliminated from India in 2005. **Hu, aged 40**, very appropriately articulated

> "*Woh sarkar leprosy eliminate kiya toh kya kiya. Humko kya mila usse. Leprosiyon walon ka toh taklif aaj bhi hai. Aap madam dekh hi rahe ho. Mota mota logon se sarkar ko toh paisa milta par hamara kya. Sarkar ke liye toh leprosy ka kahani khatam 2005 mein*" (Government has eliminated Leprosy in 2005. But what we received from it? People affected with leprosy are still in problems. You are seeing it with your own eyes. Big people have given money to the government but what is the use for us?)

5.5 NARRATIVES ABOUT PAIN AND ILLNESS OF PEOPLE AFFECTED WITH LEPROSY

Narratives about pathologized body by individuals are a way of taking into account how they experience their illness and what kind of meanings do they create or associate in relation with illness. In the context of stigmatizing diseases like leprosy, society associates intense negative cultural meanings which in turn carry very many repercussions for the people who are affected. Leprosy as illness becomes metaphor[62] to the lives of those who live with it every single day. Narratives have been used by those affected to order and give meaning to their experiences of living with disease and the pain[63]. It emerged very clearly from the field that 'story telling about their illness

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[62] Sontag (1990)

[63] Kleinman (1988)

through narratives' acted as a means of catharsis for most of the participants. It was an exercise which they actually did for the first time as far as they could recall. As discussed before, immense thrust on biomedical cure and treatment of diseases like leprosy has actually negated experiential dimension of 'illnesses'. It will be highly inappropriate to bring in notion of Cartesian dualism between body and self since diseased body certainly embodies various kinds of disruptions introduced in life. Stories of illness as shared by all the research participants have been saga of immense struggles and apathy of living with scourge of 'leprosy' both emotionally and physiologically every single day of their lives.

It is essential to factor in cultural meanings and societal notions attached with leprosy in order to account for 'experience of illness' in totality. Since time immemorial, leprosy has been seen as a polluting disease which afflicts those who are sinners. In spite of medical advancements, still widely held societal notion about leprosy is that is hereditarily transmitted. People affected are seen as 'untouchables' and potentially infectious in spite of being cured. A variety of these notions which are socio-economically-culturally-historically ingrained breed and perpetuate stigma. Very sight of a disabled person affected with leprosy (it is so visible) stimulates a typical metaphoric thinking in the minds of people at large. Stigma has been one of the biggest barriers in their life's which not only restricts their social participation and engagement but also their access to and utilization of basic essential services including health services. This in totality has impacted their present and past health outcomes.

Present empirical work has endeavoured to capture narratives about illness and pain as articulated by research participants. It is important to reflect here that these narratives have enabled affected individuals to coherently restore most of their life events one by one and the way illness has left life bewildered at a personal and social level. Life history approach to the study has enabled in understanding life experiences of people affected in totality beginning right from their childhood, life in native, onset of the disease, ways of dealing with it and life after disease onset.

55 year old Go shared

> "*Mere pair par kuch gir gaya toh Raichur aur Hyderbad mein Doctor ko dikhaya. Haddi dikhne lagi thi. Doctor ne operation kar pair thik toh kara par ungli sara nikal diya. Dawai chalti thi. Glucose bhi lagaya tha. Leprosy wajah se pair mein*

> *dard rehta hai. Patti bandhti hoon Safdurjung se hafta hafta ki do aati. Par kya bolna aisa ho ho gaya ab toh*" (Something had fallen over my feet. I went to Raichur and Hyderabad for treatment. Doctor did an operation. He corrected my feet but toes had to be amputated. I was under medication. Because of leprosy I get pain in my legs. I do dressing of wounds and bandages are given by Safdarjung hospital weekly twice. What else can be done also?)

While she shared all this she seemed to be absolutely undisturbed with what she spoke. She narrated like any other normal story but despair was certainly visible through her voice and expressions. Her narrative reflected a complete dissociation from physical and emotional self[64] resulting into more of injuries through self-neglect. Linguistic dispossession from her affected limbs was clearly demonstrated (*Doctor pairr ka ilaaz kiya* instead of saying *mere pair ka ilaaz kiya* which in fact other people who are not affected with leprosy will certainly assert while narrating).

About leprosy there is a widely held myth that it eats up limbs and causes flesh to rot. But instead loss of limbs is because of repeated injuries to anaesthetic limbs which cause ulceration and wounds. These injuries accumulate slowly and along with other kind of infections lead to slow loss of limbs. This mutilation is a gradual process and take years to finally take shape. Bodies are disfigured and marked for life. Intense shame is felt on account of the same as evident from sharing's made by research participants. There is an embodiment of social hierarchies experienced in the form of social consequences of leprosy. This entire process is extremely painful both physiologically and emotionally. Pain has been a chief metaphor in their illness histories, in their loss of close people and social status[65]. Chronicity of neuritis pain has been an important somatic complaint across all the participants. Surprisingly, it emerged from the field that people (men and women both) sought pain medication through various forms of substance abuse.

52 year old female research participant, **De**, expressed

> "*Mujhe bimari jawani mein hi aa gaya. Doctor ko Bellary mein dikhaya tha par kuch pharak nahin tha zyada. Delhi mein bimar hona toh Bengali doctor ko dikha deti hoon. Paan masala khana toh bhookh bhi kam. Kya na woh tension kam hota.*

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[64] Barret.R (2005)

[65] Barrett.R (2005)

> *Desi Daru lena padta. Nahin liya toh nind nahin aati aur bahut dard bhi rehta phir*" (I was afflicted with this disease during my young age. I did show to the doctor but not much change in the condition. In Delhi whenever I fall ill I visit Bengali doctor who is situated close by. I take *Paan masala* because I get less tension and do not feel hungry. I have to take country liquor otherwise I do not get sleep because of pain)

Another male participant, **MuS aged 58**, expressed

> "*Hamara nazar bhi kam ho gaya hai ab. Aankh chala gaya hai. Bacche bhi chote hain. Bas Allah ka hi sahara hai. Paisa zyada lagta operation mein toh. Utna kahan se lana. Dard kafi hota hai. Paiir mein zakhm ho gaya hai kal shyam ko (showing the same). Yahan se jar aha tha, dikha nahin aur patthar se lag gaya. Bengali doctor goli diya hai dard ki par aaram kam hai*" (My eyesight is very weak now. My children are also very young. I have only God's support with me. Operation cost is very high and I do not have that much amount of money. How to arrange so much? It pains a lot. I have got a wound on my feet yesterday. I was passing by from here, could not see and got it with the stone. Bengali doctor has given me medicine but not much relief yet)

MuS has expressed difficulties of old age which are magnified to a great deal because of manifestations of the disease. He has responsibilities of his children upon his shoulder and situations of acute poverty inhibit him from seeking treatment for his lagophtalmous eyes. He is cured with medicines for leprosy and given a leprosy negative status by medical doctor. But lifelong consequences of leprosy still continue to impinge upon his life and create difficulties in everyday life. There are many others like **MuS** who believe that only support available to them is from God. Life with pain and suffering of leprosy is inevitable for them irrespective of medical cure.

Ya is the most elderly person among all research participants. **Ya, aged 71** recalled about initial onset of the disease and narrated

> "*Ujali twacha ho jati thi. Angare samane baithne par ghaav ho jata tha. Kafi dard hota tha aur haat paiir sun ho jate the. Doctor sahib ko pehle toh nahin dikhaya. Baad mein dikhaya jab ungli mein aise aise ghaav bahd gaya tha. Ghaav itna hua tha sota waqt chuha bhi kha jata tha. Pata nahin lagta na. Dhire dhire mein gall*

> *raha tha*" (I had white spots over my body. If I used to sit in front of fire I used to get wounds in my hand. It used to pain a lot and my limbs were sensation less. I did not consult any Doctor initially. Later when wounds were more severe on my fingers I had to visit. Wounds were so much that while sleeping rat used to come and eat my flesh. I could not even make out. Slowly my body was withering away.)

Above narrative has presented one of the most dehumanizing aspects of leprosy-physiological pain exacerbated by repeated ulceration and slow withering away of one's body part. *'Ghaav into hua tha sota waqt chuha bhi kha jata tha. Pata nahin lagta na. Dhire dhire mein gall raha tha'* is sufficient in itself to express intensity of one's agony and physiological pain on account of leprosy.

40 year Sh shared with a heavy heart and deep sigh

> "*Yahan par na nas marta tha aise aise. Bahut rota tha mein. Goli khata tha. Par bhi bimari toh zyada ho gaya. Chalne mein bhi nahin hota tha. Yahan yahan aise ho gaya. Goli khaya na toh bimari aur zyada ho gaya. Bahut dard rehta. Garmi sardi bahut lagti. Bimari ana wajah se gaon se toh nikalana pada na. Yahan aakar ilaaz pura kar diya. Mujhe BP aur Diabetes ka bhi bimari hai. Dhyan toh rakhna hota na. Kuch hua toh idhar udhar dikha liye Doctor ko*" (My nerves used to ache all over. I used to cry a lot out of pain. I did take medicine but it did not help much. Disease increased even more. I used to find difficult to walk. It has happened like this on my body (showing his limbs to me). I feel too much of heat and cold. Because of the disease I had to leave village. After coming here to Delhi I finished my treatment. I have a problem of BP and Diabetes too. I have to take care more because of this. If something happens I go somewhere here only to get my check up done)

This narrative presents complexities poised by co-morbidities which exist in addition to leprosy. **Sh** also suffers from high blood pressure and diabetes which increases his vulnerability to ulceration and delayed healing even more. He shared about difficulties faced by him even in smallest of small daily routine activities. As mentioned before, medicines alone are not sufficient in giving a complete state of well being to people affected with leprosy. **Sh's** narrative also revealed about hidden dimension of leprosy cure and treatment- 'side effects'. Side effects certainly accompany but these are seldom brought to awareness of patients through a proper counselling. Intensity of side effects also becomes a reason from them to quit many a times as it happened in the case of **Sh**.

People also had their own understanding about disease implications on to their bodies and its causation. Narrative of **65 year old Fa** has been quite insightful in this direction. She expressed,

> "*Hath (hands) mein tab tak kuch bhi nahin tha itna. Hath aise hati mere (touching my hands). Sidha hata ekdum. Yeh hoke toh 6-7 saal hi hua bas. Pehle acchi thi mein. Mera ungli sara aisa hata (pointing towards mine). Takat kam hoti na jab aisa hota. Hathon, pairon mein zakhm hone lagta. Yeh hamari umar ghatati na jab haat pairon mein takt kam hoti au raise ho jata. Takat matlab abhi tumhari takat hai aur meri nahin. Umar saath takat kam hoti na waise. Jab aisa nas (nerve) mein khoon kam ho jata-tab aisa kich leti piche. Patti wala ghaav wagarah kuch bhi nahin mujhe. Chota bahut toh ho jaega. Par woh aapo aap sahi ho jata. Saaf safai toh rakthi hoon mein. Jute (shoes) pehen rakhti hoon. Sishe saaf paiir hain mere. Ungli bhi sahi hai. Bas yehi do haath mein hai. Kamar mein, ghutne mein bahut dard rehta hai. Uthne baithne ko bhi nahin hota ab. Bahut dard hota hai par kya karna ab*" (My hands were all right till some time back. It all happened just 6-7 years back only. Earlier I was all right. My hands were normal like yours. As age increases one's stamina also comes down. Because of this more ulcers start happening in limbs. Stamina means like you have it and I do not have it. When blood decreases in nerves then hand becomes like this. I keep hygiene. My wounds are not of the kind which needs dressing. I wear shoes. My feet are all right. It's only in my hands that deformity has appeared. I do get back pain and pain in knees. I find it difficult to sit and do work. It pains a lot but what to do?)

Throughout her interaction, **Fa** repeatedly kept saying '*Pehle ekdum sahi hati. Ekdum sahi saaf haath hate mere*' and kept pointing towards my hands. She did express some degree of association with her body certain times by using words like '*mere'(mine), 'hamare*' but she did not forget to point at normal hands of mine (the researcher). Shame felt on account of her mutilated hands was expressed in her non-verbal gesture and her embodying of 'healthy self' through an image of the researcher. She very categorically created a distinction between other people affected with leprosy that are severely deformed and clad with heavy bandages and her state where deformities and bandages on her body were bare minimum. It was interesting to understand from her world view about 'causes of deformity and implications of the same'. She brought in the notion of '*takat*' which decreases as one gets aged. She had clawed hands which she explained based on her interpretation of the condition. Her simplistic notion and understanding about her own illness and diseased body in simple plain words in contrast with complicated jargon filled linguistic interpretation of medical doctors is something worth noting.

Towards an end of this chapter, it will be appropriate to say that all these narratives actually enabled research participants to coherently articulate about their overall health conditions, share about how disease actually impacted their lives and how they continue to experience illness all through their lives. This chapter was meant to exclusively capture overall health experiences of people affected with leprosy and how these are in turn related with their larger life experiences. Participants sharing's enabled to highlight a wide variety of issues like factors involved in delayed diagnosis of leprosy and shaping of treatment experiences, existence of medical pluralism with a distinct pattern of resort which is hierarchical, gender dimensions interwoven with treatment and overall health experiences, treatment trajectories in Delhi and in Karnataka, nature of relationship shared between people affected with leprosy and health practitioner and importance of understanding the same, interface between biomedicine and leprosy and narratives about pain and illness. It should be mentioned here that illness narratives of the participants have been one of the component of their entire narrative about their life experiences. Beauty of the chapter has been that each of the research participants had a unique life story to share which was articulated in their own voices with a wide diversity of experiences. This helped in better analysis of what they shared and expressed.

CHAPTER 6: CONCEPTUALIZATION OF DIGNITY AND EXPERIENCES OF STIGMA IN THE LIVES OF PEOPLE AFFECTED WITH LEPROSY

A state of well-being with an optimum level of functioning is produced not only bio-medically but also socially. Fulfilment of basic human needs which are both emotional and material, attainment of a status of respectable dignified human being, economic situations, cultural norms and beliefs- all contribute in producing a sound state of health among people. On the contrary, negative forces such as stratified nature of the society with graded inequalities, hegemonic power relations, stigmatizing attitudes and behaviours, various forms of indignities, discrimination, humiliation, social exclusion and exploitation impedes the growth of human potentials to its fullest. In the lives of people affected with leprosy, 'diseased state' has continued to persist in spite of medical treatment. A perpetual state of ill health continues to exist for them which is medicated through a range of socio-economic-cultural factors. There is deprivation not only at material level but also at the level of emotional needs. They continue to be confronted with experiences of intense stigma and live a life of indignity '*amaryaada*'. This has immensely affected their conceptualization about self as a full and equal human being who is worth being respected. Iniquitous access to and utilization of resources is related with the same. Treatment as 'a sub-human' with various kinds of labelling and stereotyping has triggered many life processes/events with a very distinct moulding of life trajectory. These situations directly impact health of the people at various levels - physical, mental, emotional and social. As a public health researcher it becomes even more important to understand what impacts health of the people affected with leprosy in spite of being 'cured' and how. This can be understood to an extent by making an attempt to understand conceptualization of dignity and a range of experiences of stigma in the lives of people affected with leprosy. Here, it is important to bear in mind that one is not claiming about gaining full understanding about lives of people affected with leprosy based on these two concepts alone but it allows one to understand some of the hidden dimensions of their life impacting health directly or indirectly.

Narratives of research participants spread across various stages of their life. This has enabled them not only to articulate about their life in their own words but has also acted as a means of catharsis for some of them. As clearly expressed by some of the research participants, '*In life so far, neither anybody asked them about their life nor they tried thinking about the same with so much of effort*'. Utility of 'participant voice' can be better understood with an epistemological standpoint. This perspective maintains that the less powerful/disadvantaged members of a society have a more encompassing view of their social reality than others because their disadvantaged position grants them a certain epistemic privilege over others[66]. Their life realities and situations can be best understood through them only. In the field, once the participant began sharing all life events, experiences, instances were recalled in a natural free flowing manner and narrated like one long story which is full of many crests and turfs. In this chapter, an attempt has been made to present sharings made by research participants in their own words based the concepts of stigma and dignity. Nature of experiences was so varied and intensity of the same was so deep that it was felt to analyse them all together as a separate chapter.

6.1 DIGNITY AND LIVES OF PEOPLE AFFECTED WITH LEPROSY

Present research enquiry began with a focus on stigma and life experiences of people affected with leprosy and their interface with institutions of the society at large. Interest was to explore concept of stigma and its various consequences in the lives of people affected. In the process of reading, discussions with people in the field, observations and pilot field visits, purview of research enquiry began to broaden. It was decided to understand not just stigma as manifested in the lives of people affected with leprosy but also try to understand conceptualization of dignity in actual experiential terms in their lives.

It is very crucial to understand and realise that dignity acts not only as a 'condition' but also as an 'enabling force'.[67] In a simplest possible sense, dignity implies a person feeling one's worth and value in himself/herself with a complete sense of being a respectable human being. But again, dignity is not separate from social context and situations.

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[66] Guru (1995;2549)

[67] Deshpande.M (2006;3)

As it is observed from field observations and interactions, there are two levels of existence for people affected with leprosy: one is at the level of an individual who suffering from leprosy and another is at the level where an individual is a part of the larger community of people affected with leprosy involving an association of self with the commune identity. Phrases like '*hum toh sab kodhi hain yahan*', '*yahan sab mangta hai*', '*hum kodhi colony ke log*' (we all are lepers here, here everybody begs, we are residents of leprosy colony) signify the same. '*Kodhi, Bimar, Lachar*' is a shared identity by all people affected with leprosy residing in a leprosy colony with shared indignities of life impacting their entire idea about being a complete human. Thus, in developing an understanding about dignity in relation with people affected with leprosy it is very important to transcend the boundary of individual to an understanding derived from collective sense of dignity and its interpretation at a commune level.

In the field, '*touch and acceptance*', '*aspiration for children: next generation*' and '*livelihood*' were seen as few of the pathways which can bring in dignity for the people affected with leprosy. As observed in general, many of the people affected with leprosy prefer going to private practitioners and Bengali doctor for many reasons. As explained in the previous Chapter 5 one of the chief reasons is attitude of the health practitioner. If people perceived indignity in any form or any kind of stigmatizing behaviour and attitudes, they preferred to quit that practitioner and visit someone who values and respects them. People's sense of dignity is inter-twined with all kinds of social interactions wherein economic and cultural factors have an important role to play.

Now based on field observations and narratives of research participants, an understanding gained above will be illustrated.

Go, aged 55, shared

> "*Mein sochti hoon ki yeh rog mujhe kaise aa gaya? Bhagwan kaise kar diya mujhe aisa? Mein bhi kabhi kaam karti thi par ab.........(long pause). Meri itni buri halat ho gayi hai- mujhe bahut lagta hai. Kai baar lagta hai ki yeh mere ko aise kyon aa gaya, log bhi bolte rehte hain. Marne ko tha mujhe- yahan aa gayi phir mein pati saath*" (I do think that how I got afflicted with this disease? How come God did this to me? I too used to work once upon a time but now........... My condition has worsened so much- I feel about it immensely. Many a times I think that how come this happened to me? People also tell the same and rebuke

> me. I was almost on the verge of dying- then I came here to Delhi along with my husband)

Her narrative is reflective of many questions which were expressed by other people in the field as well in different ways. Self-mortification is akin with her life because of realization about here diseased and physically marked body. She does remorse about her present life and indignity which is brought to her because of the public rebuke, social segregation, diseased and marked body and begging. It was immensely difficult for **Go** and for many others to actually even think about 'oneself as a human being with dignity (*maryaada, sammaan*)'. Upon being asked about her '*maryaada*' she very spontaneously replied '*maryada illa'* (no dignity). During initial few meetings she always used to fold her hands and bend down in front of me. She was repeatedly asked not to do the same. But overtime it was understood- reasons for her such a repressed and humiliated gesture. It was an outcome of intense indignity meshed up in social relations with which she was confronted every single day of her life. Her gesture and silence was testimony to a deep painful saga of her 'indignified dehumanized life' entrapped in a physical body which is recognized as 'diseased and heinous'. Her inherent worth as a human being is long forgotten which has completely impaired her sense about self and conceptualization about her dignity.

Another research participant, **De aged 55**, very clearly brought the dimension of indignity brought to oneself because of begging[68] as a means of earning which they are compelled to choose. She narrated,

> "(After a long pause she spoke)........................ *Mann mein kya ajib sa lagta hai. Mein acchi thi Yeh kaise ho gaya mujhe? Mein Karnataka mein acchi thi. Hamara nasib mein hi bheekh mangna likha hai so hua. Mangte waqt mann mein lagta hai aaj bhi par kya karna. Pehli baar jab mangne ko gayi tab bahut ajib hua mujhko. Sharam aati- kaise karna aise yeh? Apne gaon mein nahin kar sakte na. Mera nasib hi aisa hai. Mangne ko accha nahin lagta par kya karna padta. Hum bhi pehle tumhare jaise hua karte. Ab kaise kya dekhna- kya maryada?*" (I used to feel very bad within myself. I used to think- I was completely all right. How did

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[68] Indignity associated with begging by people affected with leprosy has existed historically. They have been always seen as a public nuisance and agents of disease spread.

> this happen to me? I was happy well settled in Karnataka. My fate only is cursed. It is written in my destiny to beg and earn a living. While I beg even today I feel bad but after what to do? For the first time when I begged I felt very bad. I felt embarrassed- how to do like this? I cannot do like this in my own village. My fate is cursed. I do not like to beg but I have to. I too was like you before. Now, how to even think of my respect. my dignity?)

It should be noted in above narratives (**Go and De**) that an expression of indignity exists in past tense. As said before there have been various verbal and non-verbal symbolic expressions of indignity which they have underwent in life. Over time, these expressions have only got deeply routinized in their lives and accepted as fate. But yet deep down their heart a very strong craving is still alive which pleads to be treated as a human with no differential treatment. This is very important to note here because people from the field including research participants did express to be treated as a full and equal human being and not as a leper or beggar or *bimar*. For some of the research participants, these interactions were one of the rarest platforms which they ever had to express and share about themselves as a human being.

MuS, aged 58, highlighted another aspect associated with dignity, in relation with goodness of heart and not being sinful. He expressed

> "*Maryada matlab mein dil se rakhta hoon. Dil yeh mera bura nahin hai. Yeh bimari toh mujhe kaise ho gaya? Kabhi bhi hum kisi ka bura nahin kiya-chori nahin ki-kisi aurat ko bura nahin bola-phir kaise ho gaya humko. Ab zindagi toh barbaad hona. Ab kya kaam kar sakte? Mangne ko jana nahin toh dusara koi kaam nahin*" (For me dignity is related with goodness of my heart. My heart is not bad. How come I got afflicted with this disease? I never thought ill of anybody. I never stole anything. I never abused any women. But still I got afflicted with this disease. Now my life is ruined. What can be done also? I have to beg because there is no other option for me if I have to survive.)

An expression of indignity in above narrative is based on conceptualizing dignity as a quality associated with one's honour because of good work and attributes. This conception of dignity where it is seen as 'acquired' because of one's work is ingrained in social relations where it is often forgotten that every human being is born with an inherent inalienable 'human dignity' which is not related with one's work or qualities or attributes.

It was worth noting that research participants like **Ya (aged 71)** stammered and was speechless when he was asked to share about his '*maryaada, gaurava*'. But when same probe was asked using the word '*amaryaada, agauraava*- what makes him feel indignified', he could share at great length. This instance is sufficient in itself to understand intensity of indignity which he has underwent over his life time right from the time his disease status was disclosed among people. He shared,

> "*Kya samjhte Madam!! Bol bhi nahin sakte ab. Hamein toh sab ho gaya. Mein sab kuch chod diya. Hamara baccha log ko bas sab acche se ho. Lag bolta hai bahut. Par kya karna. Hamara kismat mein hi aisa ho gaya hai. Bhagwan ko soch kar bas jite hain. Kaam karne ko nahin deta- kodhi bol bhaga deta hai log. Kya karna toh phir. Maryaada kaise kahan hona phir?*" (What to say Madam!! I cannot even speak. My life is over like that. I had to leave everything. I only wish that now my children grow up well. People rebuked me immensely. What to do then? My fate was destined to be this way. I cannot work. People also throw me out. What to do? Where is my dignity in such situations?)

Narrative of **Ya** very clearly illustrates the linkage between stigma experienced in the life of people affected with leprosy and conceptualization of dignity by them. Various experiences of stigma do impact them adversely in many ways and their sense about self as human. Neither society is willing to acknowledge there inherent worth as a human nor are they able to think of themselves as complete human being with right to live life with dignity like others. **Ya** also revealed few important components of dignity through his narrative: education for children, work availability and respect for oneself and family. In the field, it was often observed that people affected with leprosy associated their conceptualization of dignity with dignified life for their children. Sharing by **Hu, aged 40**, reflects the same

> "*Humko toh ab jivan kar diya. Ab kya hai baccha logon ko padana likhana. Acche se kaam dhandha mein laga dena. Shaadi bahar kar acche se set karna ab. Hum toh mang kar jivan kar diya par baccha logon ko nahin karna ab aise. Hum kodhi jaise jivan kara. Baccha saath aisa kaise?*" (My life is over like this. Now all I want is that my children study well and live their life with dignity. They should

> work respectably. It's time for them to settle with respect. I have spent my life begging but I want a better future for my children. I have been looked as a leper all through my life but I do not want same fate for my children)

One observation was made in the colony at multiple instances during fieldwork time. This enabled to understand indignity underlying in charity activities which happens in the colony. An example being, food distribution activity in the colony by donors. It is not easy for anybody to stretch one's hand for food. In a big crowd each one of them is competing over other to get their share of food by stretching their hands to the person who is distributing. This is how they have continued to receive food for the years without any dignity and they find nothing unusual about it. But as an observer, I could see deeply entrenched indignity in stretching hands to get food whenever it was given. One of the participants, **Sh aged 40**, expressed availability of food in Delhi as one of the good things which happened in his life after migrating. He expressed,

> "*Accha toh yahan ho gaya na. Khana pina milta yahan par. Accha hai sab. Bhukha nahin rehta yahan par ab. Koi koi daani log akar dekar jata. Ho jata hamara*" (Here one of the good things which happened is availability of food. I get it in plenty here and I do not need to go to sleep hungry. People come and donate food here often. It is sufficient for me and my family)

Indignity is not just about rebuke, discrimination but it is also experienced in very unseen forms- going to sleep hungry is also a form of indignity which is seldom recognized. Narrative of **Sh** signifies the same.

In the field, dignity was also associated with economic security. **Fa, aged 65**, narrated

> "*Atmasamman kya- mein toh kuch bhi nahin sochte apne bare mein. Kya hamara toh ab ho gaya (spoke hurriedly in a desperation) – hamari toh ab umar ghat gayi. Abhi beti-damaad aur bacchon ke liye jine ko hota. Kuch ek paisa do paisa jama kar unko acche se kar deo. Maryada mane wahi kal ka aaj aur aaj kal rakhna samjh kar. 10-5 rupay bhi picche rakhte. Thoda mein hi sansaar karte jate hum. Doctor aaye toh prem se dekhe. Safdurjung se gadi aata aur kutte ko jaise phekta waise do patti phek kar jata. Humko accha nahin lagna aise*"(Self respect- How can I think about it? My life is over now. Iam getting old. Now, it's time for my daughter and son-in-law. I live for them. If I can save money it is

> good. It will be help them. We are not rich. We manage our life with whatever bare minimum we have. If doctor treats me all I want is that he should look after me with love and respect. I do not like when this van comes from Safdurjung and people simply throws bandages as if we are dogs)

Fa continued to stress on education of children, good life for her daughter and son-in law, and ensuring financial stability by saving some money. Her narrative is one clear illustration of most de-humnaized form of life which exists for them on a daily basis. She used a comparison with dog in order to express the way bandages are given to them. Compromise with such situations of extreme indignity is driven by situations of extreme helplessness. It is essential to think about such kind of situations existing over lifetime where health as a right is denied in various forms- from very covert ways to very overt display. Conception of dignity based on ontological source is clearly reflected from her further sharing

> "*Mangna aasan nahin tha humko. Hamein dukh ata tha. Hum kaise paida hue aur kaise kaam kar rahe. Pehle koi kuch bole toh bura lagta tha. Vichaar ata- kya karna? Hamara kismat hi aisa hai bolkar hum samjhate. Ab toh dukh hone se kaam nahin chalega. Aaj mein kuch bhi humko dard nahin hota. Aakhir kitna hona? Ab apne mann se hum mang rahe hain (with an insensitive tone she spoke)*" (Begging has not been easy for me. I used to feel very sad. I was born differently and see what Iam ending up doing now. Earlier when people used to rebuke me I used to feel very bad. I used to accept it as an outcome of my destiny. Now by being sad it won't do. I do not feel pained at all as of now. After all how much? Iam begging presently as per my wish and choice)

Fa is compelled over the years to actually dissociate herself emotionally from indignity underlying in an act of begging. But she felt extremely ashamed when she begged for the first time in life and was highly reluctant to do the same for a long time.

Having said that, it is necessary to recognize a very slow and settled process of dehumanization of self where people affected with leprosy actually cease to be seen as dignified human beings. Dignity for them is graded as less in comparison with those who are not affected with leprosy. This is in dire contradiction with entire ontological origin of dignity which not only undermines there valued self but also restricts their human potentials, choices and freedoms.

After understanding various conceptualizations of dignity and components of the same as shared by research participants we now move to an understanding gained about their life experiences in relation with stigma.

6.2 STIGMA AND LIVES OF PEOPLE AFFECTED WITH LEPROSY

As it is evident from literature review, stigma is a dialectical social process which is produced and perpetuated in a particular context. Term stigma needs to be deconstructed and seen at the level of causes, forms and its manifestations in the lives of people affected with leprosy. Moreover, it is necessary to move beyond an understanding of 'leprosy related stigma' where stigma is seen to be exhibited only because of leprosy. One needs to factor in both individual and community level experiences of stigma in a holistic manner in relation with overall experiences of life. From the field realities and literature review, it is clearly evident that leprosy coupled with existing socio-economic inequalities, gives a solid foundation for stigma to thrive and to manifest. An attempt has been made to understand actual experiences of stigma in the lives of people affected with leprosy as expressed in their words.

As mentioned before, experiential understanding of people affected with leprosy about experiences of stigma is built and shaped by various contextually ingrained factors. It is to be noted that for all the eight participants and especially for four women participants, it was immensely difficult to actually articulate about their understanding, emotions and experiences of stigma. With years of being humiliated, discriminated and excluded, it was like a catharsis for them to actually recall their life story where there has been multiplicity of instances where they were stigmatized in a variety of ways. Their initial silence was evident of their pain and experiences which was slowly verbalized through words. Following sections present a narrative account of the same. It is important to bear in mind that although these experiences are categorized in to four different sections for an ease in understanding but in real life they often overlap and impact one another.

6.2.1 ANTICIPATED STIGMA

Anticipated stigma connotes to what an extent people affected with leprosy, anticipate or fear the possibility of being stigmatized. It should be understood here that this anticipation or fear does not simply exist. It has settled down within their minds mainly on account of familiarity about the treatment which is given by the society to a person affected with leprosy. As revealed by the research participants and other people from the field, there was always a fear in their minds that 'other people' will adversely react to them. Anticipating the same, concealment of initial signs/symptoms of the disease or denial or deliberate no self-disclosure was exhibited. Disease kept progressing causing an irreversible physiological damage. Medical treatment was sought only when it was too worse to hide and tolerate. They further added that now their anticipation about people's negative reactions has come down because of being accustomed to it for so many years. They themselves take 'precautionary measures'. Right from the times when leprosy visibly started marking their bodies, a withdrawal from social interactions has occurred.

One of the female participants, **Go aged 55**, shared

> "*Mein tumhare jaise acche (swasthya) logon ko nahin chuti. Dooor se hi baat karna. Hum dil se pehchaan lete na. Mann ka pata lagta hai. Tum (addressed to me) jab aati ho toh pata lagta hai ki tumhare mann mein kuch leprosiyon ko lekar nahin hai. Isiliye mein tum ko chhu liya. Dusaron ko nahin chuenge. Hum bimar, kodhi hain. Acche logon ke pass kaise. Woh nahin aata*" (I do not touch people like you who are healthy. I talk to them from a distance only. I can recognize heart of the person. When you come, I can make out that you have nothing in your heart towards people affected with leprosy. That is why I touch you. But others I do not. Iam ill, a leper. How can I go near healthy people? They too do not come).

Another participant, **De aged 52**, reiterated the same

> "*Tum (addressed to me) chute ho toh tum bhedbhaava nahin karti ho. Door hath ja nahin bolti. Mein accha samaj se alag hi rehna. Woh log alag. Hum kodhi log se nahin. Mein bahar bazaar jati tab chunni se lapet leti hoon. Woh dikhata na*" (When you touch me you do not discriminate. You do not yell 'get away'! I remain isolated from healthy people. They too remain separate. We are lepers so how can it be possible? Whenever I go out to the market I cover myself with my *dupatta* so that my deformity is not visible).

In the field it was observed that none of the female participants touched me and came close to me until I made them feel comfortable and expressed clearly about the fact that Iam not at all concerned about their disease status and a deformed body. Initially, all of them used to speak to me with their folded hands from a distance and some women trying to cover up their bodies in order to hide deformities. They all anticipated a certain set of reactions from me as well based on their previous experiences where they were always rebuked and treated like untouchables.

6.2.2 SELF STIGMA

Self or internalised stigma signifies negative beliefs about oneself, and in the case of leprosy it is related with a particular health condition which is highly stigmatized. This is further mediated by conditions of poverty, cultural practices, societal norms and beliefs. Knowing and understanding to what an extent these negative beliefs have been fathomed by people affected with leprosy is important because this in turn shapes and influences their life choices and trajectories. For this the best way is to understand perceptions and beliefs articulated by people affected in their own voice.

In many ways, disease status signified with leprosy has shaped their mechanisms to deal with their real life situations. Perceptions about self have been distinctly shaped after the disease onset and diagnosis. As reflected through **40 year old Hu's** sharing

> "*Humko bimari aa gaya tha. Ghaav tha aur deformity bhi aa chukka tha. Sab kamata aur haemin baith kar khana accha nahin lagta. Humko sharam ata tha. Humko toh aisa ho gaya na ki mind mein dhila hone laga. Sab chod hamara pura mann mein aisa ho gaya aur Delhi ko aa gaya*" (I had disease. Ulcers were there and deformity had started to appear. Everybody used to earn except for me. I did not like to sit at home without earning. I used to feel embarrassed. I was upset because of this. I left everything and came to Delhi).

Among some, there have been feelings of guilt or shame because of deformed bodies which in turn makes them feel different from other people who are not affected with leprosy. **65 year old Fa** shared

> "*Pehle bimari nahin sahi hate tumhare jaise, Haath pehle tumhare jaise hathe mere. Abhi aisa hua hai. Sharam lagta hai. Ab tumhara haath aisa na aur hamara kodhi logon ka kaisa. Ungli nahin. Kuch nahin. Aisa kaise. Log dekh bhaga deta hai. Aisa kaise hona. Mein yeh saree aisa pehen rakhti thoda chup jata na usiliye. Pairon mein juta pehnati. Ghaav bhi nahin aata aur chup bhi jata*" (Earlier when I was healthy I was like you. My hands were all right like yours. Now only it has happened like that. I feel embarrassed. Now your hand is like this and our hand is

> like this. We are lepers. No fingers in limbs. How can it be? People see us and drive us away. I wear this saree in such a way that it can hide my deformity to an extent. I also wear shoes. It not only protects my feet but also hides my deformity in feet).

It was not just **Fa** alone who indicated an embodiment of her healthy self through me by repeatedly pointing at my limbs and then relooking at hers. It is imperative to understand self-mortification among people affected with leprosy as an outcome of mutual reinforcement of societal rebuke and permanent physical marking of the bodies. A public branding is tagged upon individuals and groups who are seen as socially discredited.

It is apt to say that in the lives of people affected with leprosy stigma has been amplified under the conditions of poverty and social alienation. Situations of poverty, ostracism, exclusion coupled with affliction with a stigmatized health condition like leprosy, yielded situations of utmost desperation. On account of experiences of self-stigma which exists in unison with the way society perceives and reacts to people affected, changes have been incorporated in various domains of their life like work, education, socialization etc.

As **Hu aged 40** expressed

> "*Humko chota umar mein hi bimari aa gaya tha. Mein 15 saal ka tha tab 10th mein padta tha. Pehle toh safed chatta aya pura body par. Par jaise jasise bimari bhada hum ko taklif hua. Padai bhi chut gaya phir. School mein bhi sab bolne laga tha. Humko toh aisa ho gaya mann mein nahin jana ab karke. Bahut mann mein aisa aya karke ki logon se door rehna. Humne yeh pura decide karke baad mein ghar bhi chod diya aur Delhi ko aa gaye*" (I was very young when I got afflicted with the disease. I was 15 year old that time and was studying in 10th standard. Earlier there were white patches all over the body. But as disease progressed, I was in more pain. I had to drop out from my studies too. People in the school used to pinpoint at me. I was very sad because of the same and did not want to continue anymore. I decided to segregate myself socially from people. I decided like this and later left my home too.)

Another participant **Ya aged 71** shared

> "*Hum toh kya na apna gaon mein Bellary mein ata, wahan rehta tha aur kheti kar peth bharata. Bimari aane se haath pairon mein thanda garam pata nahin chalta. Chot lage toh bhi nahin pata chalata aur ghaav ho jata. Bimari ana wajah se kheti hum chod diya. Koi kaam nahin kar sakta. Kamane ko mushkil that toh biwi bacchon saath Delhi ko aa gaye. Yahan akar mangna shuru kiya. Humko mann mein baut aise ho gaya*" (I used to stay in my village in Bellary. I used to do farming. Once I got the disease I could not sense hot-cold with my limbs. I used to get hurt and wounded since my limbs were anaesthetic. I had to leave farming because of the disease. I could not do any work. It was difficult to make a living in Bellary so along with my family I came to Delhi. Here I started begging. I used to be sad and embarrassed because of the same).

A tendency to 'alienate oneself' from the larger processes of the society has been observed in the field. As mentioned before, stigmatization is a dialectical social process. So this 'alienation' is also an outcome of a relationship shared between stigmatizer and stigmatised which is highly iniquitous and problematic. Stereotype endorsement has been akin to 'self-stigmatisation' wherein people affected with leprosy actually start to believe in the stereotypes held in the society towards them. Repeated affirmation of the sentence "*Hum toh kya karna. Kodhi hain. Lacahar ho gaya*" (What we will do. We are lepers. We are disabled) reflects internalization and acceptance of set stereotypes and labels. There has been a certain degree of normalization of stigmatizing situations by rationalizing them with a justification. Narrative of **MuS, aged 58**, reflects the same

> "*Hum toh kodhi log hate. Log aitraaz karta hai. Karne deo. Kya karna toh phir. Koi hoe toh bolkar bhi jata. Sunata tum kodhi, lachaar, bimar ho karke. Hum sunana toh phir. Ab kya karna bhagwan aisa kar diya haemin toh. Kodhi hai. Log karta toh karne deo. Kuch kaam bhi nahin kar sakta. Kodhi hai hum koi kyon kaam dena humko?*" (People address us 'a leper'. They also take objection to us. Let them do. What can we do also? Some people rebuke us also. They say that you are a leper, disabled, diseased. We just listen. What can we do also if God did this to us? After all, we are lepers. If people object against us let them do. I cannot work either. Why somebody will give me work? Iam a leper.)

In certain cases, a feeble attempt to overcome 'self-stigma' has been also observed.

Ya, aged 71, shared

> "*Log toh kya aitraaz karna. Idhar nahin baithna. Udhar nahin jana. Yeh Kodhi hai Kodhi hai karke bolna. Gadi (train, bus) mein hum jana. Jo baithna hoe woh baithna. Hum toh baith ke jana hi. Hum kyon uthana wahan se. Hum SC hai. Koi kuch karna toh Police mein jakar complaint kar sakte hum*" (What people do – they keep instructing not to go there, not to sit here etc. They address by saying he is a leper. I go in public transport like bus and train. If people have problem with me being there what can I do. If they want to sit they sit else they get up. Why should I get up from there? Iam scheduled caste SC and if they rebuke more I can file a police complaint against them)

It is important to bear in mind that anticipated stigma as discussed in the previous section can also be one of the outcomes of 'self-stigma internalized for years'. So if **Go** and **De** anticipate exhibition of stigma from others who come to them and tend to isolate themselves, then deep down there is also a feeling of diminished self-worth and endorsing of stereotypes that people affected with leprosy are infectious, heinous and untouchables. This is again shaped in a particular context in any society with distinct historical background, cultural practices and economic conditions of life of people affected.

6.2.3 EXPERIENCED STIGMA AND ITS IMPACT UPON THEIR LIVES

As evident from the field, social construction of leprosy has influenced shaping of dominant public imagination about leprosy and people affected with it. This has in turn contributed in determining and concretizing various experiences of stigma among those affected. Experienced stigma cannot be quantified but it can be best understood qualitatively through narratives of people affected. Exploring nature of discrimination, instances of denial and non-acceptance, multiple axes of disadvantages and presence of various exclusionary measures enables to understand in detail impact of stigma upon the lives of those affected.

Various conditions of life not only lead to amplification of stigma but also creation of situations where choices are made amidst sheer desperation to sustain. This is in reference with begging by people affected with leprosy where in begging becomes a sole means of meeting daily essential needs. Beggary is also accompanied with creation of multiple intersecting identities, one of them being 'heinous leprous beggar'. A person affected with leprosy and especially the one begging on the streets is reduced from a complete and usual person to a discredited, discounted one. This label of 'discredited' associated with an individual and groups becomes one of the biggest handicap in the lives of those affected leading to dehabilitation in many cases. Over the years, endorsing the set stereotypes and fathoming the stigma held against them. it becomes in the 'interest' of so called discredited to actually capitalize on their popularly believed identities amidst situations of no opportunities for social integration.

One of the participants **Ya aged 71** expressed

> "*Delhi mein kya kaam hai. Sirf bheekh mangne ko hota hai. Kuch kaam nahin kar sakta haath pairon se. Koi deta bhi nahin. Kaise kya karenge. Kuch toh karna pade jivan chalane ka liye. Nazar bhi kam hai. Bheekh toh mangna hi padta na. Ghar par rehna se accha do paisa kama kar ana roti lane ke liye. Gaon mein nahin mangna pehle. Log kodhi bolta. Bhikhari karke aise bhagta. Kya karna phir*" (In Delhi there is no work except to beg. Iam not able to do any kind of work. People also do not prefer to employ me. What to do then? Some work has to be done to earn a living. My eyesight is also weak now. I have to beg. It is better to earn a little by begging rather than just sitting at home. People do rebuke by calling a leper of a beggar. What to do then?)

Another participant, **Me aged 50**, shared

> "*Pehli baar mangna mein nachli thi- yeh kaisa mangna karke. Kaise hoega karke lagta. Dandapani mera pati mang raha toh mein chip kar gadi mein bathegi. Dandapani gadi mein lekar jata mein chip kar baihthi. Accha nahin lagta. Phir band kar diya. Mere ko bahut pareshan aya. Bahut pareshani pareshani hai. Mangne ko jati mein ab bhi. Koi bhi nahin hai. Aamdani kuch nahin. Pension nahin. Sharam toh ata bahut. Pehle kabhi nahin mangti mein. Kitna bhi hoe toh Rs 50-100-150 kamana. Din din ka pharak hai. Kabhi accha hoe toh kabhi kuch bhi nahin. Admi bhi nahin. Bahut mushkil hai. Gaon mein jata toh nahin bolta hum Delhi mein kya karke*" (For the first time when I began begging it was very difficult for me. I used to think how I will do it. My husband Dandapani used to beg and I used to sit hiding in the cart. I did not like doing so. Afterwards I stopped going for begging. I have been very much troubled financially. Nobody was is there to earn. There is no pension either. I used to feel very embarrassed. I

> never begged before. It's only now after coming to Delhi. I get to earn maximum Rs 50-100-150 a day. It fluctuates from day to day. My husband is also not alive. Life is very difficult. Whenever I go back to my village I do not reveal what I do in Delhi).

Stigma is not only faced by people affected with leprosy siphoned off into begging but also by their children. They also undergo feelings of shame on account of means of earning which their parents have resorted to. One of the days while I was in the field, **MuS aged 58,** had gone out for begging. His 14 year old son was around. I enquired from him about **MuS**. With an expression of embarrassment across his face, he replied "*Baba bahar gaye hain*" (He has gone out). When I enquired more he tried to avoid the question but then answered "*Bahar gaye hain kaam se. Roj jate hain subah mein aur dupahar tak aa jate hain*" (He has gone out for some work. He goes daily in the morning and comes back by afternoon). Rather than affirming with his own mouth he just answered indicatively which was sufficient enough to understand what he meant. This was not the case only with the son of **MuS** but many other children in the field actually avoided answering this question whenever whereabouts of their parent were enquired.

Experiences of humiliation and denial of basic human rights in various forms is synonymous with 'life of a leper- way they are recognized'. A very silent form of violence is associated with their life which in Paulo Freire's term is 'silence of oppressed'. They continue to suffer without posing any strong visible resistance. There is routinization of violence in their lives over the years which is not necessarily physical. In the field, it was most difficult for all the research participants to actually express and verbalize their experiences of stigma. There have been innumerable of them spanned across every domain of their life that 'where to begin from' was a thought provoking question for them. Response of one of the participants **Fa, aged 65**, very aptly captures the same "*Kiis cheez ki shururat? Kya batana? Kya bolna? Hai jaisa hai. Ho gaya jo hona tha. Ab kya karna*" (Starting of what? What to tell? What to say? Things are they way they are. Whatever had to happen has happened. Now what to do?)

Multiple trajectories of vulnerabilities gain prominence amidst inter-sectionalities of caste, class and gender. Denial is present in every form (material and emotional) is deeply entrenched in their life experiences. Cascade of life events after the disease onset and diagnosis has only fed into existing situations of inequality, exclusion and poverty. Stratified nature of the society has lead to intensification of experiences among those from lower most socio-economic background. Contexts certainly mediate shaping of the nature and intensity of stigma faced.

One of the female participants, **65 year old Fa** shared

> *"Hum toh garib log hate na. Roz jane ka kheti badi karne ka. Sara kheti kaam hum log karte the. Hamara thoda khet hata phir majoori ko bhi jate the dusare ke khet mein. Maa baap garib hate aur pade likhe bhi nahin. Bimari aake saal hue par pata nahin chala kafi samay tak. Itna paisa bhi nahin hata. Hum garib log. Yahan Delhi mein bhi mang mang kar gujara karna. Kuch bimari hoe toh pass mein Bengali ko dikha leti. Kam paisa leta woh*" (We are poor people. We used to depend on earnings from daily farming. My parents used to do farming in their own small patch of land along with farm labour rendered to bigger land owning castes in the village. Neither my parents were educated nor me. Disease afflicted me for many years. But we could not make out for a long time. We did not have that much of money also. We are poor. Even in Delhi also I survive by begging. If there is some health problem I visit Bengali Doctor who charges less).

In this narrative[69], it is important to note her chronic poverty afflicted conditions of living both in Karnataka and Delhi, and this has certainly mediated her experiences of stigma. Neither she nor her parents were educated and thus lacked any kind of awareness about the disease. This unfamiliarity and neglect lead to her disease progression which was diagnosed much late when deformity had already occurred. And in the given situations of her chronic poverty, negative social experience of leprosy was only intensified. She herself said during one of the conversations

> *"Hum bhi bade ghar se hota, pada likha hota toh yeh sab kyon hona hota. Hum garib hate. Mang mang kar jivan chalate. Kaun sonata hamari. Log sunata hai. Hum sunana aur kya karna*" (If I would have been from a rich family and educated then I would have never suffered like this. I was poor and still Iam poor. I earn a living by begging every day. Who listens to us? People come and rebuke. I just listen. What else I can do either?)

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[69] It is important to bear in mind that these narratives are illustrative of people's life situations who are affected with leprosy and residing in RK Puram Leprosy colony.

It is important to recognize role of the context like poverty ridden situations, inability to access and utilize services on time, lack of education etc in shaping of leprosy experience and impact of stigma. It is a matter of who is worst affected in given situations of life?

Narrative of **Hu, aged 40**, gives an insight into linkages between stigma, caste and health which holds true even in the case of leprosy. He expressed

> "*Hamra na chota gaon hai. Scheduled Caste (SC) zyada hain wahan. Bada city mein toh itna pata nahin lag pata na. Hamra jaat toh chota jaat hai. Hum SC hain (kept repeating many a times during the conversation). Abhi khane pine se koi matlab nahin hai- aisa doctor toh bol diya na. Par log bolta hai chota gaon mein rehnewala woh meat khata hai na- Beef- usase zyada kuch hota hai inn logon ko. Yeh leprosy ka bimari ussi se hota hai. Log bahra bota hai yeh chota jaat wala aisa waisa koi bhi meat khata hai na isiliye inko bimari hua. Gaon mein aisa bada log nahin khata hai wahan zyada. Yeh log bakri, murgi sab ka meat khata hai na isiliye unko nahin hota*" (Ours is a small village. SC people are more in number. In bigger city, one cannot make out much. Iam from a lower caste. Iam SC. Now, of course doctors have said that leprosy has nothing to do with eating habits. But, people in small villages believe that because of eating unusual kind of meat like beef, we people get leprosy. Leprosy is more prevalent among SC because they eat unusual kind of meat and food. But, richer people in the village do not eat such things. They eat mutton, chicken and are not afflicted with leprosy)

It is interesting to note the perceived linkages between disease causation and food eating habits of SC community and consequent stigmatization. **Hu** also shared about 'class variation' which existed in his village. In his village, people from higher caste and class were healthy i.e. not afflicted with leprosy and did not eat 'beef'. His reference to '*Bada city mein toh itna pata nahin lag pata na*' indicatively also presents prominence of caste-based identity in smaller places like his village.

Looking at the role of religion in shaping of social experience of leprosy is also important. Field setting comprised of people dominantly from Hindu religion. Hindu[70]

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[70] In Hindu Dharmashastra also discrimination towards people affected with leprosy and their out casting is clearly mentioned.

participants shared about religion based discrimination to their leprosy status which they had faced in their native place. **Go, aged 55,** shared

> "*Hum toh Hindu hate. Yeh bimari aana baad humko hath paiir mein ghaav hona laga. Ungliyan bhi kharab ho gayi hati. Humko gaon ka mandir mein ana se mana kar diya. Humko kushta rog hata na. Log bolta tumhara pichle janam ka paap wajah se tumhare ko kushta ka bimari hua*" (Iam Hindu by religion. After I got this disease, I started to get wounds in my hands and feet. My hand fingers and toes were deformed. I was not allowed to enter village temple since I had leprosy. People used to say that I got this disease because of my sins of past life).

A co-relation between karma of past life and affliction with leprosy and associated consequences of the same in the present life was established among those who were affected with leprosy. And this co-relation was more prominent in the case of participants who were Hindu.

There have been various experiences of negative reactions or actions exhibited by other people or society at large termed as 'enacted stigma'. In certain cases, relatives of people affected with leprosy also suffered stigma and negative reactions exhibited by the society. This is termed as 'courtesy stigma'. Stigma has immensely impacted lives of people affected with leprosy at an individual and community level (See the figure 6). But here one need to realise that situations in society are socially discrediting rather than personal attributes. Stigma is actually ingrained in nature of relationships in a society rather than attributes of people. In Goffmanian sense[71], it connotes a special kind of relationship between attribute(s) and stereotype.

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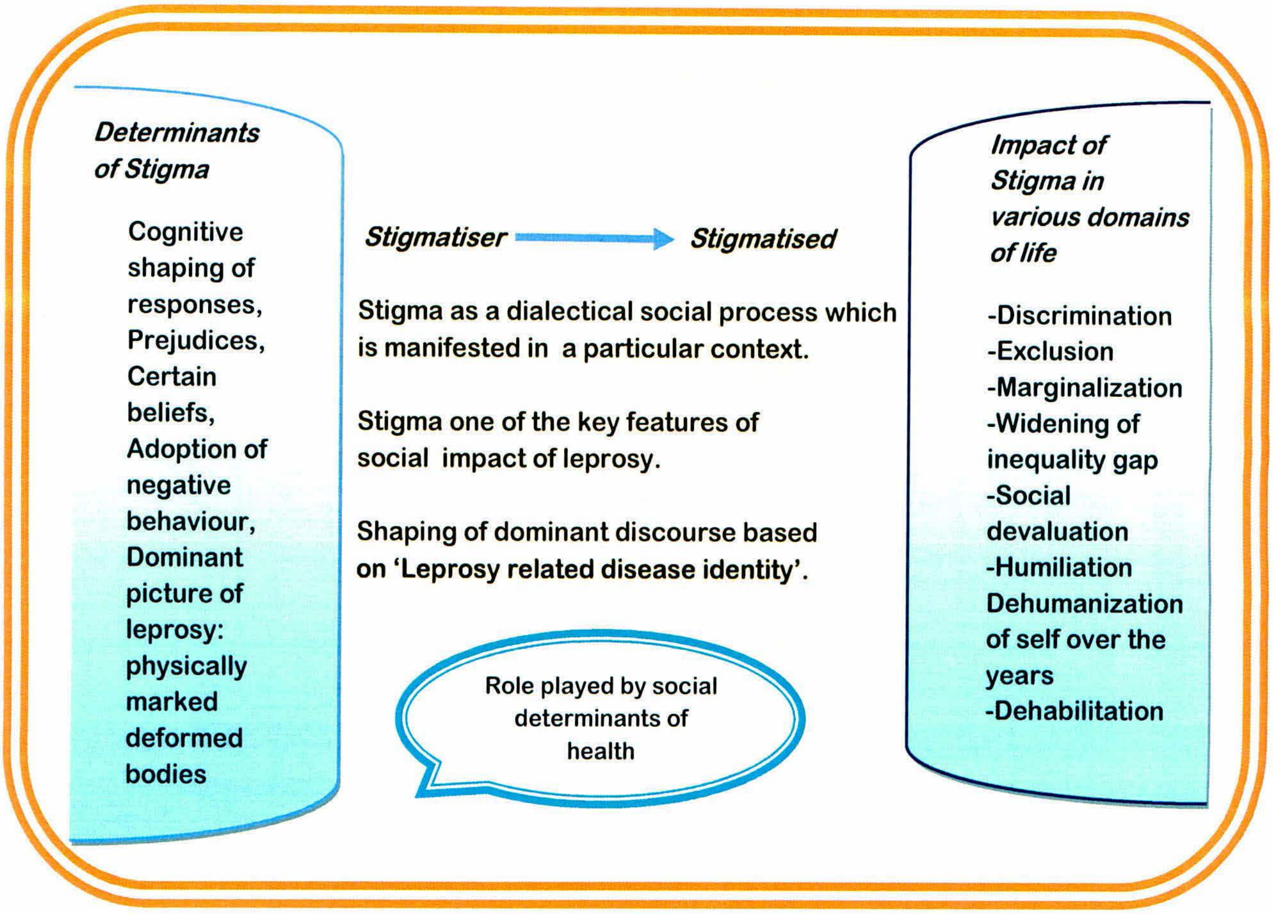
[71] Goffman.E (1963 ;6)

Figure 6 Stigma in the lives of people affected with leprosy as understood from the field



At the level of stigmatiser, there are two aspects to display of stigma. One is cognitive where people affected with leprosy are perceived as 'discredited and untouchable'. This brings us to second aspect which is a behavioural manifestation of cognitive component. Preconceived notions, biased attitudes are manifested through emotional reactions towards people affected with leprosy in the form of denial, objection, non-acceptance, rebuke etc. Negative behaviour is exhibited in various ways. There is an expression of 'social distancing' too. This distancing is also one of the contributing factors to ghettoisation of people affected with leprosy leading to formation of 'stigmatized neighbourhoods' as perceived among people outside.

Go, aged 55, shared about negative behaviour exhibited by people in her native village towards her. She said

> "*Log bolte the Indik sari ninga byani bedeti- door har ja tujhe kushta rog hai. Gaon mein log aise aitraaz karta tha. Maa baap kuch nahin bolte mujhe. Mere pati bhi bimari wale hate. Woh mujhe bhedhaava nahin karte kiase bhi. Hum saath saath rehna bimari wala dono. Delhi aane baad hum dono yahan akela rehna. Bacche mere Bangalore mein rehte apna parivar saath. Phone par baat hota*" (People ask me to get away. People used to object in my village. My parents never used to object or discriminate me. My husband is also affected with leprosy. He never discriminates against me in any form. Both of us are diseased and stay together as husband and wife. After coming to Delhi, only two of us stay here. Our children stay in Bangalore with their families).

De, aged 52 shared

> "*Mera pati ko bhi bimari tha. Pati saath sab thik tha. Shaadi time mujhe itna bimari nahin hua. Usse aise koi parehsni nahin thi mere se. Woh mujhe pyar karte. Hamara rishta parivar waalon ne karaya. Parivar mein sirf ek behen hati. Woh hi mujhe chod di Bellary Hospital mein. Pati saath rahe hate. Usko accha nahin lagta mein bimari wala hua dekh ke. Woh maa ko bolti isko hatao. Gaon mein toh log bahut aitraaz karta. Bhedbhaava pura hata. Gaon mein log nal ko pani se dhokar pakadte. Woh bole ki yeh kodhi hain- tujhe bimari hai- haemin bhi tere se bimari lag jaegi tere se pani bharne se. Karnatak mein log bahut bolta ki door hat ja (repeatedly said). Woh swasthya samaj rehna hum toh kodhi hona. Kothi bunglow ka log haemin kaam nahin karne bulate. Tum kohi colony ka log aur kodhi karke bolte*" (My husband also had this disease. Everything was fine between me and my husband. He didn't have any problem with me. He used to love me. Ours was an arranged marriage. In my family I had only one sister. She only left me in Bellary Hospital. My husband was with me in the hospital. My sister did not like me because I had disease. She used to tell my mother to send me away from home. In village also people used to object immensely. Discrimination was very intense. If I had touched community tap then people used to wash it before using. They used to hurl abuses at me and say that you are a leper- you have this disease- from you we too will get infected. People used to object to me a lot in Karnataka. They are healthy people and we are lepers. We have different life worlds. Here in Delhi, people do not let us work as main in Bungalows etc because we are lepers and resident of a leprosy colony"

Two narratives presented above bring many underlying issues into limelight, some of them are clearly articulated and some are just indicatively expressed. There has been stigmatization not only at the level of the society but in the case of people like **De** it also existed at the level of family. 'Family' itself becomes a place for stigmatization to originate and which eventually becomes one of the compelling reasons for them to leave the house. It should be noted that among all the research participants whosoever was stigmatized within the family, it was not by parents but by brothers or sisters. In the case of **Sh, aged 40**, more than people from neighbourhood it was his brother and sister-in-law who stigmatized him and eventually he was left in a situation with nobody to look after him. He shared

> "*Bimari toh mujhe bahut ho gaya. Maa Baap koi nahin. 8-9 saal ka tha tab bimari aya mujhe. Karnataka mein bahut taklif hoti uss time par. Bhai ka saath rehte pehle. Bhai ka phir shaadi ho gaya. Woh alag ho gaya phir. Bhai toh kabhi kabhi aitraaz karta par bhai ka biwi na woh aise aise mana karte the. Aise apna apna aa gaye. Hum akele reh gaye wahan par. Kya karne ka phir. Mang mang kar idhar udhar se khaya karta. Bahut pareshani hua tha. Sab aitraaz karte the. Isilye toh yahan Delhi aa gaye. Aisa sab bolta bhai ka biwi bhi ke isko bahut bimari hai. Isko accha nahin hai. Yahan par nahin baithana isko. Bolta ki tum jao yahan se. Tum yeh raaste se mat aya karo. Aise jao wiase jao bol bol karta sab log. Bhedbhaava bahut ho gaya humko*" (I was 8-9 years old when I got afflicted with this disease. I had no parents. Over time it increased a lot. Life was very tough for me in Karnataka. Earlier I used to stay with my brother. But once he got married he separated. My brother used to object sometime but my sister in law had more problems with me. I was left alone. I used to make a living by begging here and there. It was very difficult. Everybody used to object including my sister in law and brother. They used to tell me not to sit here. You are not healthy. You go away from here since you are diseased. You do not go through this way. Like this people used to keep objecting and discriminating)

A variation in intensity and nature of stigma is also brought to fore by **De** and others in the field. According to them as compared to their native-rural Karnataka, situations in Delhi which is an urban city are comparatively better. Stigma exists in both the places but comparatively in Delhi it is less intense.

Among all the research participants, except for **Me,** no one else faced stigma from their spouse. In the case of **Me,** her first husband who was healthy had stigmatized and left her. **Go and De**, both have/had husband affected with leprosy. This created 'similarity of life situations' in couple relationships which also leads to an optimum level of understanding and co-operation as expressed by both the women. Same was shared by two other women participants as well (**Me** had re-married with a leprosy affected man). **Fa** said "*Aisa na tha ki hum toh unki bimari mein dekhte the aur woh humko*" (We used to mutually look after each other in suffering). Similarly, Me also expressed "*Bahut pyar karta tha humko Dandapani. Bahut pareshani hai unke bina. Hum dekhte aapas mein*" (He used to love me very much. Now life is certainly tough without him. We used to mutually look after each other).

Objection and discrimination in the native place was also expressed by male participants. This actually became one of the many reasons for them to migrate either singly or with family. **MuS aged 58** narrated

> "*Aitraaz toh log karna shuru kar diya jab unko bimari bare mein pata lag gaya. Log aitraaz kiya toh phir hum nikal gaya wahan se. Parivar wala kuch nahin bolta. Par padosi bolta ki kya yeh bimari wale ko rakha hai ghar mein. Iske ghar se lena dena kyon rakhna. Aisa sunn sunn ke hum akela nikal gaya aur Hospital ko pahunch gaya. Wahan akela rehta mein auron ke saath mere jaise*" (People started to object once they came to know about the disease. Since people objected very much so I left my native place. I came to the hospital and stayed there alone along with other people of my kind who were also diseased. My family did not object me. But neighbours used to constantly rebuke me and tell my family that why you have kept this leper. They stopped communicating with my family)

Narrative of **MuS** highlights one very important aspect of enacted stigma- stigma expressed towards family members of person affected with leprosy (Courtesy stigma). Family is socially ostracized or boycotted because of the presence of 'a leper'. **Fa, aged 65,** also shared about experience of her family members who had to face stigma on account of her presence. She said

> "*Behno ab bade gaye the. Hum ghar par rehne se unko koi bhi shaadi nahin kare- koi bhi nahin aate the. Kyonki bimari toh thi aur sabko pata lag gaya tha. Pehle kheda mein aisa hi hata. Itna jaan pehchaan nahin hona, panda likhna kam hata.*

> *Mote mote logon ka majuri karne ka aur khane ka. Doctor toh bola ki bimari nahin badega ab par log na yeh bimari ko thoda darte the. Maa Baap kya ho gaya na ki unko pata lag gaya ki Bellary mein Missionary Charity ka Hospital hata. Jab yeh aisa hoke woh log phir Bellary mein* ***chod*** *kar gaye mere ko. Umar tab 25 saal hati meri. Chod ke jane se hum aisa dekh lo hamara nasib toh kharab ho gaya. Aur dusare koi bhi humko shaadi nahin hoegi aur naahi gaon mein rahegi. Bahut pareshani tha"* (My sisters had grown up. Because of me being at home nobody was willing to visit us and marry them. I had disease and everybody had come to know about it. It used to be like that in villages earlier- people were not much educated, were poor too. In spite of doctor saying that disease will not spread people were still scared of the disease. Because of existing situations, my parents left me in Missionary of Charity hospital in Bellary. I was 25 year old that time. After they left me, destiny continued to play an evil game with me. No one was willing to marry me. There were too many difficulties)

Hu, aged 40, too had a somewhat similar story to share. He said

> "*Yeh jab leprosy start ho gayein na toh gaon mein logon ko pata toh chal gaya. Mann mein kuch toh log sochta tha aur kuch pyar bhi karta tha hai. Hamara parivar waalon ka mann mein kuch nahin tha. Sab clear tha woh log toh. Aaspass rehne wala aitraaz karta. Log bolta ki aree iska ghar mein aisa rogi hai. Iska ghar mein mat jana-inse mat lena. Agar naujawan ladka ladki how aur shaadi karna hoe toh uska kaam nahin hoga. Log bole ki arre iska ghar mein ladki ko mat deo karke kyonki yeh kodhi hai. Ladki ko log bolta ki uske ghar mein shaadi mat karo karke. Mera parivar se sab baatcheet band kar diya. Chai pina-baith ke baat karna sab band tha. Kehte ki aree nahin uska ghar mein rogi hai. Hum kaise jana wahan? Hamara shaadi time bhi ladki joh humse prem karta uska maa baap use khub bola kit um aise kaise isse prem karta-yeh rogi hai garib hai chota jaat ka hai! Par woh nahin mana aur humse shaadi bana liya*" (When I afflicted with this disease people had come to know about it. Some used to think in their mind and some used to negatively behave also. In my family, nobody every objected towards me. My neighbours used to raise objection. They stopped visiting my house and warned girls from marrying me since Iam affected with leprosy. People stopped communicating with my family. I had a love marriage. Parents of my wife also objected towards me but she persisted on her decision).

Hu's narrative presented above speaks of a very common problem encountered by people affected with leprosy in terms of marrying and getting or continuing with a life partner. In the case of women, situation is much worse as already discussed in section on leprosy and gender in Chapter 4. Either they are unable to marry or get to marry a leprosy affected man only or deserted by their husbands if they are healthy. **Me, aged 50**, shared about her life experience of being deserted by her first husband who was healthy

> "*Shaadi toh jab 18 saal ka tha tabhi ho gaya. Shaadi hona baad bimari zyada ho gaya. Ek baccha aya na ladka uska baad. Aur meri pati chod di phir. Woh acche hona. 20 saal umar thi tab. Bimari aaye the na toh woh jae rahe. Baad mein phir wapis aaye. Ladki de diya mere ko aur phir wapid chod di. Phir nahin aayi wapis*" (I was 18 year old when I got married. After getting my married my disease progressed even more. My son was born when I was 20 and disease intensified during that time. My first husband who was healthy left me after seeing that. Later after some years he again came back. I gave birth to a daughter after that. But again he left me and never came back).

Fa's narrative presented above also brings in a component of fear which people till today harbour against people affected with leprosy and the disease itself. Fear not only generates social distancing but also negative behaviours loaded with various prejudices and myths. There are beliefs that by sharing common space like community tap or visiting affected person's house or eating with them etc will lead to affliction with leprosy. Even in Delhi, people affected with leprosy and their family members are denied work in Bungalows or elsewhere on the grounds of leprosy background. In this context, **Ya aged 71**, shared

> "*Gaon wala bahut aitraaz karta. Mereko narraz ho gaya aur sara chod kar yahan Delhi aa gaya. Log bolta pani nahin chuna. Baccha saath khana nahin khana. Koi nahin dekh raha tha. Sab log darta tha humse. Hamara maa-baap-bhai log toh kcuh nahin bolta tha. Hamine log kehte the ki arre tere ko yeh kaise aya.Tu toh kodhi hai. Kya karna phir humko. Kheti chod diya aur Delhi aa gaya sab chod. Yahan par bhi log aitraaz karta hai par kam hai. Kothi mein kaam ko jaayein aur pata lag jaye toh haemin aur hamare ghar waalon ko bhi mana karte hain. Bus mein ya gadi mein jayein toh log kodhi dekh samjh uth bhi jata*" (People in the

> village used to object. I got annoyed. Left everything and came to Delhi. I used to do farming before. People used to say not to touch community water source. Not to sit with their kids. Not to eat with them. Nobody was looking after me. Everybody used to get frightened of me. My family was all right with me. People in the neighbourhood used to say – Oh! you have leprosy. You are a leper. I came to Delhi after leaving everything. Here also people object but it is comparatively less. If I or any of my family members go to Bungalows seeking some work – we are denied work).

Hu, aged 40, shared about a very strong instance about his life in Delhi in terms of denial of work opportunities and an option to earn a living with dignity. His leprosy status became a strong ground for denial of work opportunities to him which was very covertly expressed. But finally after much of struggles he did manage to get job of sweeper with MCD but for past seven years it is contractual only. He shared in detail

> *"Bellary se sidha Delhi aya naukri ki talassh mein. Par kuch kaam nahin mila. Paise idhar baithne se kahan se ana? Jivan toh chalana tha. Hum mang kar jivan shuru kar diya tab. Bheekh mangne par sharam lagta humko. Kab tak mangne ka? Thoda din Beggin kiya aur useke baad Madam (Susham Swaraj) thoda madad kiya humko. 2003 ka Health Minister Sushama Swaraj tha. Woh BJP ka tha aur state Congress ka tha. Uss time mein woh madam se humne request kiya ki Madam hum bhi 10th pass hoke pada likha hai. Hum bheekh mangne mein sharam aata hai- thoda bahut humko kaam dhandha mein lagao. Chota kaam ho toh bhi hum karke denge. Thoda din Ward boy ka kaam kiya Primary health centre mein. Phir Madam ne Leprosy Section (Chattu Pandey) officer ko bol diya ki inko kaam pe lagao. Ab bolne ke baad mein 3 baar letter aya humko Nirman Bhavan se 2003 mein. Health minister humko madad karne ke liye pura taiyar tha. Akri final mein kya ho gaya paise ke thode lafda ho gaya matlab woh log paise puchne shuru kar diya. Hum kahan se deo- hamne bol diya sir hum begging karte hain. Hum begging karne humko accha nahin lagta isliye hum kaam karne chahte hain. Madam se baat ho gayi- humko kaam de do. Officer log humko bol diya ki abhi vacancy nahin hai tuk jao karke. Yeh sunn hum chup chaap ho gaye humko dukh ho gaya. Uske baad ek din Punjab Kesari paper mein dekha humne jo Kushta rog se pidit nahin hai woh accha 2-3 saal leprosy ka treatment lekar bilkul negative ho gaya uska pass bhi medical certificate wagarh hoga uske liye MCD ka kaam*

milega. Woh paper mein dekh ke cutting karke hum hamare pass rakh liya. Uske baad employment darz kiya humne. Ration card aur pehchaan patra aur medical certificate yeh sab jama karke townhall hai na whan par jama kar diya. 3-4 mahina baad Interview letter aane ke baad mil gaye sahib se. Hamein woh bola ki Tumko haath thik nahin kaise yeh kaam karega tum? Hum bol diya Sir abhi lagao hum kaak karke kikhayenge! Lekin phir fail kar diya. Humko woh phir bhi fail kar diya. 3 baar interview tak pahuncha aur fail kar diya. Par last mein phir pass kiya. Jab accha tarike se hum interview pass ho gaye. Uske baad naukari mila 25 March 2003 mein order hoga. Humko appointment letter uss time mein mila townhall mein se. Uske baad duty join karmne mein ek hafta late ho gaya. April 1st mein Duty join kiya humne Ramesh Nagar mein. Order/circular nikala tha jis mein March 2003 mein joh join kiya unka pukka karne ka adesh de diya. Humara order 25 March 2003 ka tha aur hum 1st April 2003 mein Duty join kiye matlab ek hafta aage picche ho gaya. Bol diya tum 1st April mein duty join kiya isiliye tumhara pukka nahin ho sakta. March 2003 mein jo duty join kiya uska order hai yeh. Sarkar ne toh aisa order kar diya. Woh unki wajas se late hua tha, minister ne order kar diya par bhi appointment letter dene mein late kar diya unhi ne. Ussi samay jab meeting hoga 25 March 2003 tabhi 5-6 logon ko apne haathon se appointment letter de diya aur baki logon ko bol diya daftar se le lo apna apna appointment letter. Hum daftar mein gaya 2-3 baar, letter nahin mila. Letter toh sara samne dekha hai hum. Issi wajah se nahin de raha. Woh chahiye yeh hoga woh hoga. Phir dusara aadmi wahan ka Shahdara ka aake letter dilwaya. Ussi wajah se 1 hafte late ho gaya. But in spite of all this he takes a deep sigh and says 'Thoda bahut paisa kharch ho gaya par kuch nahin. Naukri toh ho gaya"(Summary: I had come straight from Bellary in search of a job but I did not get any. How to sit here empty hand with a responsibility of my family? Something had to be done. So finally I started begging. I used to feel embarrassed while doing the same but there was no other option. I requested Sushma Swaraj to help me a little who was health minister in 2003. I have studied till 10th standard. On her instructions I was placed with primary health centre as a wardboy for sometime. Then she asked Leprosy section officer to give me some work. I received letter from Nirman Bhavan thrice. Before it could be finalized-one problem arose. Those people started asking for money. I refused since I was poor and it was not possible for me to give the same. Officers told me that there is no

> vacancy so you go back. I was silenced after that. One day I saw an advertisement in Punjab Kesari paper which mentioned about provision of job with MCD for people who are medically leprosy negative after receiving treatment. I went to town hall with all the documents. After 3-4 months I received an interview call. Officer over there told me that since you have problem in your hand how will you work. I said confidently that I can and you give me any task I will finish it. But still I was failed in interview. Thrice I reached final interview but could not make it. Finally I cleared my interview and job order was issued on 25 March 2003. But they further delayed in giving appointment letter. So finally I could join from 1 April 2003. In the meantime one government notice was issued according to which all contractual workers were to be regularized who had joined uptill March 2003. I was not regularized since appointment letter was delayed to me. But still Ok. At least I could leave begging and earn properly now.)

This in-depth narrative presented above is exemplary in terms of struggles of people affected with leprosy to earn a living with dignity free from stigma and its demeaning impact. In this case, **Hu** wanted to quit from begging and to get job of a sweeper with MCD he had to struggle immensely. Even after all those struggles he is still serving at the lowermost cadre of work with Municipal Corporation of Delhi (MCD) on contractual basis for past ten years. But for him this is the source of his happiness and satisfaction because unlike others he does not need to beg to make a living. He is at least free from the stigmatizing identity of 'a leprous beggar'. He is able to manage his life well with Rs 7000/- he gets along with his Rs 1800/- monthly pension. He himself expressed "*Hum khus hain ab bahut. Begging chod diya hai*" (Iam very happy since I have quit from begging now). In fact this is the dilemma which confronts most of the people affected with leprosy- even if they want to quit from begging, is there any other option available for them to earn a decent signified living? It is not possible for them because stigma of leprosy and their lower socio-economic background coupled with cultural beliefs continues to haunt them all through their lives.

6.2.4 IATROGENIC STIGMA

Iatrogenic stigma[72] refers to stigma exhibited in health settings or institutions by health professionals towards people affected with a particular stigmatized health condition, leprosy in this case. In another way it can be put as stigma which is generated in a biomedical encounter between the patient and the health practitioner, which can either be felt or enacted. Not to forget here, context plays an important role in generating, mediating or perpetuating this stigma.

As evident from Chapter 5 about treatment experiences of people affected with leprosy, various forms of stigma in health settings crucially affects treatment seeking behaviour of those affected, their adherence with treatment regimen, disease diagnosis and cure. As mentioned at the very outset of this section on stigma, various forms of stigma do overlap and impact each other. Recognizing the role of various health settings and health practioners in contributing to the same needs to be recognized. As shared by people, stigmatizing attitudes and behaviours more very prominent in government healthcare institutions. One of the participants **(Go)** had mentioned about being admitted to a government hospital in her native but she was asked to stay out in the corridors instead of general ward with other people who were not affected with leprosy. What one is trying to say here is that in spite of biomedical facts available about the disease, various kinds of prejudices, myths, and biases even among healthcare professionals continues to add to overall experience of stigma of people affected with leprosy. This is clearly illustrated by an experience sharing by **Sh aged 40**,

> "*Delhi aane baad bimari toh zyada tha hi. Zakhm tha haath-pairon mein. Yahan par dawai bhi le liya. Guru Teg Bahadur Hospital (GTB) Shahdara mein bhi dikhaye the logo ke bolna par. Wahan par kya hum kodhi log karke dekhte hi nahin. Doctor hoe nurse hoe compunder how bahut chillata hai. Door se hi goli phek kar deta. Chune ko bhi mana karta. Hamein accha nahin lagta. Private mein paisa lagta par aisa toh nahin. Bahut hua toh Nirmal ya TLM ka Hospital hai. Bengali humko dekh leta pass mein hi. Paisa bhi kam lagta*" (After coming to Delhi my disease worsened much more. There were wounds in my limbs. Here I

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[72] This term was coined by Cassandra White in 2008 in her article *Iatrogenic stigma in outpatient treatment for Hansen's disease (leprosy) in Brazil*, published in Health Education Research, Volume 23, No 1, pg 25-39.

> took medicine. Somebody had told me about GTB Hospital in Shahdara. I went there too. But there I was discriminated. I was treated as a leper. Doctor, nurse, compounder- all of them yell at me. They throw medicines from a distance rather than giving in hand. They refuse to examine us by touching. I do not like this. In private I have to pay but situations are at least better. I go to Nirmal or TLM hospital also at times. Most of the times Bengali doctor is there to treat me. He charges also less).

As evident from the narrative above, in the realm of dominant 'purchased privatized health care' and 'weakened government health institutions', a poor ill person is the one who suffers the most. And especially in the case of stigmatized diseases like leprosy where health-related stigma and various forms of societal stigma override the recognition and addressal of patient's needs. Although private practioners charge high amount but they do not stigmatize them and treat with dignity. Charitable and missionary run hospitals are other viable options. Christian philosophy towards people affected with leprosy is embraced by these missionary and Christian voluntary run organizations which in turn attracts many of those affected with leprosy. Cost is involved in both the places but here at least they are treated with dignity without being stigmatized. As mentioned before in Chapter 5 of people affected with leprosy, majority of people in RK Puram leprosy colony resort for treatment to Bengali Doctor who is situated close by. One the main reason is his complete acceptance without any stigmatization towards people affected with leprosy. Thus, amidst situations of stigmatizing biomedical encounter of people with health practioners and privatized medical care, only viable and affordable option left with people affected with leprosy is informal health practioners. Cultural beliefs and faith in their cure also drives choices of people affected. Narrative of **Hu, aged 40,** is illustrative of the same.

> *"Yeh Doctor hota hai na hamara jankari mein ek tarah se Bhagwan ka roop hota hai. Hmara jankari mein jo mariz jata hai na, Doctor ka farz banata hai ki use bachana-thik karna-izzat dena. Hum sidha Missionary Hospital mein gaye the. Wahan Doctor acchi tarah se dekhta maa-baap tarike. Sarkari mein uska baad ek saal gaye the. Missionary hospital mein 2 saal dawa khaya bhi. Bilkul acche se aur pyar se dekhta Doctor. Bilkul bhedbaava nahin karte the. Itna pyar se woh dekhta na ki maa baap bhi nahin dekhte. Par Sarkari mein toh aisa kuch nahin hota humko. Koi koi Docotor accha hoe toh hoe. Yahan par Bengali doctor hua*

> *woh bhi kuch bhedbaava nahin karta. Humko leprpsosiyon karke nahin leta bilkul*" (In my knowledge Doctor is one of the forms of God. It is the duty of the Doctor to take care of his patients with love, care and respect. I went straight to Missionary of Charity Hospital. There Doctor look after patients very well like your own parents. They love all their patients. They do not discriminate at all. But in government nothing of this sort exists. Bengali doctor next to our colony does not stigmatize us at all. He does not look at us a leper.)

This narrative clearly highlights importance of positive and constructive relationship which is shared between Bengali doctor and people affected with leprosy from the colony. It also brings in a contrast between attitude of practitioners in government health settings and missionary run health institutions. This was articulated by other residents from the colony as well.

Thus, one can clearly see impact of anticipated, self and experienced stigma onto lives of those affected with leprosy. These are clearly interlinked and overlapping with each other. At large in the society people affected with stigmatizing health conditions like here leprosy are socially disqualified based on bodily conditions with a complete negation of their human existence and dignity. One should bear in mind that health related stigma does feed into intensification of societal stigma at a macro level. Stigma engulfs not only people afflicted with the disease but also their family members. Bodies are marked for life which also creates negative self-esteem about oneself. Illness becomes a key metaphor to their life. As a public health practitioner, understanding about stigma and dignity in the lives of people affected with leprosy becomes even more important. Stigma attached to diseases like leprosy contributes immensely to hidden burden of illness. Even after successful cure, manifestations of leprosy continue to impact their rest of the life. People affected are even exiled from hope and compelled to embrace loneliness and stigmatized socialization within the confinements of neighbourhood which by name itself as '*Kushta Ashram*' is stigmatized. All this is certainly generated, mediated and perpetuated in a context which is social, economic, cultural, medical, historical and political in nature. It is important to bear in mind, inter-sectionalities between stigma, leprosy and social determinants of health like caste, class, gender, religion especially in an Indian context. There are various trajectories of the processes with which social disadvantages are further deepened and thus contribute to further marginalization of people affected. Situations in the field very clearly and strongly illustrate the need of considering experiences of stigma and conceptualizations of dignity for research, health policy making and clinical practice.

CHAPTER 7: FINDINGS AND DISCUSSION

Through this empirical work an attempt has been made to understand and explore various domains in the lives of people affected with leprosy residing in a leprosy colony of south west Delhi. There are three main focus areas of research study

- Understanding various domains of life experiences of people affected with leprosy and factors which influence the same.
- Understanding the varied nature, different experiences and impact of stigma as manifested in the lives of people affected with leprosy.
- To build an understanding about the conceptualization of dignity and notions of self-esteem by people affected with leprosy and various factors which influence the same.

Focus in this chapter is on recapitulating various issues and aspects related with lives of people affected with leprosy that have emerged from the field. Attempt has been made to weave together empirical findings from the study with existing literature. Additionally, newer insights which have developed have been highlighted. Some questions are also raised which have entirely emerged through data analysis and field experiences, for further reflection and future research. Present study is representative of a unique life world of people affected with leprosy residing in a leprosy colony geographically located in Delhi. It can be certainly used as a basis to corroborate with other studies or settings in relation with leprosy. An attempt has been made to harmoniously blend theoretical conceptualization with field work and yield better insights.

7.1 METHODOLOGY ADOPTED IN THE PRESENT STUDY: A DISCUSSION

While at an initial stage of conceptualizing this research, based on field situations, it was deliberately decided to incorporate participant perspectives with an emphasis on sharings made in their voices. Both the sexes have been included in order to better understand how leprosy affects lives of men and women and understand overlaps-disjuncture's which exist in experiencing the same. This kind of gender informed approach is seen as useful for a larger purpose of appropriate interventions, programmes and policies made in relation with people affected with leprosy. Various dilemmas were also there in relation with choice of field site, sampling of research participants, choice of appropriate methodology for the research in order to best capture experiences of people affected with leprosy. But all of these dilemmas were resolved over time by field situations itself. This was supplemented with intensive literature search too.

Methodologically, present empirical work relies on life-history approach with a narrative enquiry which is the differentness rendered to this work. Endeavour has been to holistically capture major life events of eight purposively selected research participants beginning from their past (as far they can recall) to their present. In leprosy discourse indeed there is a mix of research studies available with clinical approach, quantitative, qualitative and mixed method type. In qualitative research studies, most often case study method or interviews, focussed group discussions are used. Staples.J (2011b; 109) writes that in the field synoptic life history accounts and case studies of people affected with leprosy tend to follow a set way of narrative forms where disruption of life processes by onset of leprosy is usually explained. Often much of emphasis is laid on leprosy related stigma and identity at expense of other forms or factors contributing to social exclusion. Rather effort should be on achieving a more nuanced understanding through intensive biographical accounts. Staples draw this interpretation from his own ethnographic work wherein people affected with leprosy are seen to be with multiple intersecting identities and a great diversity of life experiences. And of course this kind of research methodology has remained underused in studies of social experience of leprosy. Stigma conjured up with leprosy does not exist in vacuum rather there are certain situations and contexts which drive and propel the same in the lives of people affected with leprosy. And stigma is not the sole domain which needs emphasis but there are multiple life events and related phenomenon's over time which need an equal emphasis but are often left out in popular leprosy discourse. Staples.J (2011b;110) very appropriately comments

"In terms of capturing the lived experiences of people affected by leprosy, however – and, consequently, in understanding the impact of the leprosy stigma – they often obscure more than they reveal. Life stories can also serve as bridge between the polarities of structure and agency, culture and voice, by documenting not simply the

capacity of individuals to act, but the converging contexts in which those actions are shaped."

Thus, as observed from the field also various narratives constituting overall life history accounts of all the research participants enabled not only to see their life situations as a whole which is beyond leprosy but also acted as a means of venting out/expressing one's innermost feelings and emotions. This articulation about their lives was a means of catharsis for them where they were given a chance to reconstruct all broken pieces of their lives and articulate them in a most spontaneous natural free flowing manner. One checklist was prepared which guided course of interaction which was adaptable as per each of the research participant. Except for life history accounts documented by Staples through his ethnographic work none of available work which I encountered actually emphasised in looking at life histories of people affected with leprosy with an element of 'wholeness'. This research study was certainly not an ethnographic research. But during field work over a span of time multiple rounds of interactions were made with participants in a free flowing manner. Innumerable observations during various occasions and social gatherings like Christmas event, Maha Shivratri festival etc enabled to get a minute understanding about the lives of people affected with leprosy residing in this colony and their neighbourhood interactions.

In the present study, life history approach has enabled to look at lives of people affected in totality all inclusive of their various life processes and events. At large research studies which I have come across during the course of this research have focussed mostly on one major aspect with some inter-connecting links or passing references. Staples.J (2011a; 91-92) very clearly articulates the need and utility of qualitative insights in understanding the complexity and diversity of life experiences of people affected with leprosy. He states that such kind of research does not begin with pre determined hypothesis which needs field testing and validation, rather it permits field realities to unfold. Use of an appropriate research design and a correct approach has a real potential to enhance understanding about how leprosy is socially constituted and experienced for a whole range of social actors. Present study began with an assumption based on readings and interactions with field practitioner. This assumption was further modified as field realities started to unfold in order to capture life experiences of people affected with leprosy as minutely as possible.

Some insights which are available in an Indian context in the form of ethnographic accounts with an anthropological approach is from the work of Staples.J (2003, 2005, 2007a,b; 2011a,b) spread across almost three decades in Bethany colony in Hyderabad, Andhra Pradesh. Work of Barrett.R (2005) was conducted in North India (Varanasi) is focussed on studying healing practices of an unorthodox sect (*Aghori)* and their patients with leprosy and other socially stigmatized diseases. Poestges.H (2011) had focussed on ethnographic study of a leprosy colony with an emphasis on stigma. Harris.K (2011) had done an anthropological work with leprosy health workers in an urban leprosy project in India. Most of the work is focussed on only one or two aspects and majorly on stigma. Work of James Staples is an exception which is an outcome of his long association with the field which has enabled to highlight and focus on various aspects related with lives of people affected with leprosy residing in a South Indian leprosy colony.

Most of the theoretical work combined with practical aspect done by foreign scholars is with a uni-disciplinary approach. As mentioned above indeed there is a plethora of anthropological work on leprosy in Indian context. Work by Buckingham.J (2002) is one of its kinds which present a historical narrative of leprosy in colonial south India. Sinha.H (2000) has presented an account of leprosy in Gujarat as a medical geographer. Epidemiological study by KV Rao (1992) in Chigleput District of Tamil Nadu way back in 1982 is one of the rare exceptions where with a systems perspective an inter-discilinary approach has been used. There have been research studies by Rao.PSSS (1989, 2000, 2010) on social aspects of the disease but there are not very many scholars who are academically active in this field. There is a lack of academic work with a sound theorization and an inter-disciplinary approach. It should be also noted that a majority of research studies on leprosy available in India are either in a community setting[73] or in an institutional setting like hospitals. But lives of people affected with leprosy people in open community settings[74] are yet unexplored.

It is also important to mention here that present research study inter-twines social aspects of leprosy with a public health approach in an inter-disciplinary manner. Although this study is done in one leprosy colony but it allows an intensive study of the same given the time span of approximately seven months. This decision was taken after

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[73] This implies population of people affected with leprosy which stays within leprosy colonies.
[74] This implies population of people affected with leprosy which stays outside leprosy colonies.

one month of field visits involving many interactions across leprosy colonies in Delhi. In spite of one colony study, it has been able to highlight various issues which are intricately linked with the lives of people affected with leprosy. Indeed stigma has been also one of the research objectives but an attempt has been made to look at it at the level of causes, forms and impacts through participant voices. It's been seen in tandem with conceptualization of dignity by people affected with leprosy which is seldom explored in detail in literature related with leprosy. Findings from the present research study in no way mandates emergence of same pattern(s) across all leprosy colonies in India. There might be certain variations on account of socio-economic-political-cultural factors and geographical location need to be taken into account while moving to another setting. For example situation in leprosy colonies of Purulia, West Bengal or Patna, Bihar or in Haryana may have some variations or similarities with the present study. Study has been able to give an overview about lives of people affected with leprosy residing in a particular leprosy colony and findings from the study can be corroborated with other existing and future work. It should be noted that this is a qualitative research which is representative of a particular data set rather than generalizable across all settings at all times. A core set of issues have been dealt with in the present empirical work which emerged entirely from field realities but yet there is a scope for future in-depth exploration of the same.

Phenomenon's like migration, begging, social segregation etc are of course known in relation with leprosy. But cognitive familiarity alone is not sufficient when the work is concerned with life experiences of people. Within a limited time span and with a focussed data set present study has endeavoured to explore the same at a practical level by taking cognitive familiarity one step ahead. Some of these issues have been definitely touched upon by other scholars either as a passing reference or with some inter-connections with the theme of the work. This has further enabled in corroborating present work with other literature available. For e.g. there is extensive work on international migration by people affected with leprosy in Latin American context by White.C (2008, 2010, 2011). Some inter-connecting links of the same are also visible in the present work which involves within country migration from one state to another because of a multiple number of factors as already explained in Chapter 4.

Indeed, social experience of leprosy is very distinct. There are a range of external factors which impact overall experiences of people affected with leprosy in a particular socio-economic, cultural, political, medical and historical context (Staples.J 2011a-b, White.C 2011). Prior life situations and present a certain context which plays a crucial role in shaping of entire experience of being diagnosed and living with leprosy. And attempts to hide the disease are also futile because of its visible physical manifestations. 'Leprosy status' has been one of the major triggers which has only contributed in shaping of life trajectory in a distinct way. There has been a cascade of distinct life events which are undoubtedly inter-linked and triggered with 'leprosy status of the person irrespective of being non-infectious in bio-medical terms'. All eight life stories of the research participants presented through current empirical work are living saga of people's struggles with a deep craving within each one of them to live with a life of dignity. This craving for a dignified human life is for their future generations too. All their present aspirations are associated with their children and grandchildren's for a respectable, dignified and empowered life which can only come through education, dignified profession and life outside the colony in '*mainstream society*'. Polarities, which exist between residents of the colony and outside world, are not driven by choice or any spontaneity. Rather these are forced outcomes of situations which are multi-factorial and ingrained in specific contexts. Bearing this in mind now we proceed to next section which thematically recapitulates major findings from the study along with a discussion.

Before we begin discussion along with major findings from the field it is important to look briefly at socio-demographic profile of the research participants.

Socio-Demographic details

Socio-Economic background: In this empirical study all the research participants are from poor to very poor family backgrounds. Vicious cycle of poverty still continues to entangle their lives. Three of the research participants are Muslim, one is Christian and four are Hindu. Among Hindu participants, two are from scheduled caste (SC) group and two are non-lingayats (lower caste in Karnataka).

Education: Education level among all the research participants ranges from no education to very low level of education. Three of the four female participants are illiterate and one is educated till 4th standard in Kannada medium. Among male participants, MuS is illiterate, Ya is educated till 4th standard and Sh till 3rd standard in Kannada medium. Hu is educated till 10th standard.

Native town: All the participants are migrants from various districts of North Karnataka. Three are from Bellary (Ya, Hu, Fa) and rest of them from Raichur (MuS), Yadgir (Go), Gadag (De), Bangalore (Me) and Bidar (Sh).

Having said that, now we begin the section on findings from the field along with discussion.

7.2 LIVES OF PEOPLE AFFECTED WITH LEPROSY: A DISCUSSION

7.2.1 BEGGING AND LEPROSY

All the colony residents including research participants earn a living by begging and make feeble attempts to meet their daily essential needs. Only one participant (**Hu**) has quit begging because now he is employed as a sweeper with Municipal Corporation of Delhi (MCD) on daily wages. In an absence of no alternative source of earning and their own physiological limitations because of ill health, begging is left as an only option. Begging is rather a forced choice under certain circumstances and unfortunately for research participants these situations are perpetual. Participants had resorted to begging initially in order to full fill their essential needs amidst conditions of acute poverty but overtime it became a survival strategy for them in the realm of no other viable options. A study done in urban Patna among homeless population of beggars which also comprised of people affected with leprosy illustrates the same recognizing their vulnerability, marginalization and choices made (Cheng.C and Kumar.V 2012).

None of the participants had ever begged before the disease infected them. After infection with the disease, in an absence of treatment, leprosy related physiological manifestations started to appear visibly. This in turn triggered a cascade of life events amidst which begging became a core survival strategy for them. None of them used to beg in their native villages. It was only after coming to Delhi that begging was started. **Fa** used to beg occasionally while she stayed in Bellary leprosy colony along with her husband and **Sh** began begging while travelling to Delhi. All the men of the colony who were affected with leprosy including three male research participants continue to beg till today except for few who are employed with MCD. Wives of some of them were/are also involved in begging but not all. Children are always discouraged from being siphoned off to begging. Most of the children from this colony go to school while few are school drop outs and remain at home or do some work if they are grown up. Staples.J (2007a;174, 2007b;168) reported about a similar aspect of begging from his ethnographic work in Bethany colony, Hyderabad where in male folk migrated seasonally for begging to distant cities like Mumbai, Chennai, Delhi, Kolkata or local nearby cities. Children were discouraged to beg even in his study area. But unlike his insights from Bethany colony, in RK Puram leprosy colony there was no discouraging factor per se from begging for old, deformed people affected with leprosy. It is more under compulsive conditions like inadequate welfare measures or no alternative means of earning that are pushing them to continue begging even at a much older age.

Upon analysing the profile of people affected with leprosy who were engaged in begging, there were three categories. People who were very old, disabled and completely unable to do any kind of work, people who were comparatively in younger age group (upto 55 year or so) but unable to work because of physiological limitations and stigma attached with their condition, and at last people who were still younger but with grade 1 disabilities which were visibly not that prominent as compared with grade 2 disabilities. But in all the three categories, reasons for not being able to work with dignity were same- disabled body, diseased condition and denial of work because of social stigma. Research study in a leprosy colony of Ambala city, Haryana brings in a similar finding where with inadequate socio-economic support and help people have often resorted to beggary as a way of earning their living (Kaur H and van Brackel W 2002b).

It was observed in the study that act of begging is also sporadic for few people based on dire requirements while for majority it is a daily routine either once or twice in a day (starting early in the morning by 6am till 5pm with break in between for two hours) except for Sunday. Majority of people including research participants beg near red lights in surrounding places like RK Puram, Moti Bagh or areas near Safdurjung or AIIMS hospital. Some go to residential areas too but most of them do street begging. These sites are not permanent and changed as per specific days depending on speculations about places which can fetch more earning on that particular day. In the field it was seen that individuals who were most infirm preferred to use handcart and go in pairs to beg while rest others preferred to go singly and sit at a particular place begging alms from passersby. **De** and **Sh** prefer to beg alone because this fetches more earning while rest all go in pairs mainly because of physical incapacity or in cases where both husband and wife do begging (**Go**). A day begins typically early in the morning and ends by evening. In addition to money (usually Rs 50-100 per day) they also bring back some food or clothes etc which are given to them. In begging act, as expressed by people affected with leprosy, there are various permutations and combinations which are all flexible as per situational context. Over time, they have developed their own coping strategies by compromising and accepting it as a part of life and working out best out of it.

Staples.J (2007a;174-175, 2007b;166-168) too reported about practice of begging singly or in large groups (*zanda groups*) by people of Bethany. But a gradual shift has been also observed over time from group to single begging because of more experience with time and possibilities of better earning. 'Single begging' also offered a greater degree of autonomy which has been expressed by participants in this field study as well. People engaged in begging in the scope of Staples study too preferred different places depending on days and time.

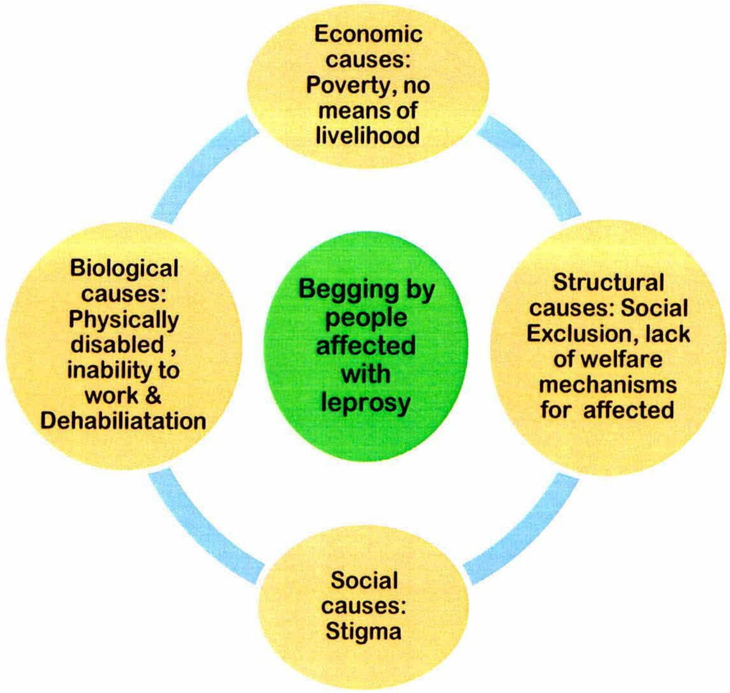
A close observation of begging by people affected with leprosy residing in the colony during one of the field visits enabled me to understand deeper dimensions associated with begging. Disabled and physically marked body is a cause of immense humiliation for them under general circumstances in life. But at the time of begging severity and intensity of ulceration with bandages and disability becomes one of the key hallmarks to attract public apathy. These are circumstances only which compels same person to act and respond differently in different situations. There is an entirely different construction of 'deformed bodies with certain symbols' by people affected with leprosy in actual practice of begging. There is a subjective construction of act of begging and interpretation of the same by non begging people (Navon.L 1998, Staples.J 2007a and 2007b).

Begging also creates one of the multiple intersecting identities in the lives of people affected with leprosy. This also impacts their conceptualization of dignity. They are recognized as 'disabled infectious leprous beggars' rather than as human beings. All the participants who were begging were dehabilitated even after treatment. This actually caused slow and settled rupturing of all their social support systems eventually pushing them into act of begging. A study among people affected with leprosy begging in Delhi supports this finding according to which various psychosocial restrictions, lack of social support and self confidence slowly pushed dehabiliated people affected with leprosy into beggary (Kaur H and van Brackel W 2002a;346). One should be aware that dehabilitation is a continuous process. As revealed through present study and study among beggars in Delhi, one can confidently say that diseased condition, impaired body, and social stigma act in unison to put participation restriction among people affected with leprosy restricting their growth potential to the fullest. This indeed leads to dehabilitation and eventually siphoning off into beggary.

It is also important to notice interface between leprosy, beggars act and law and order enforcing instruments of the state. According to Begging prevention act (1959), begging is illegal and punishable offence. Research participants shared about multiple instances when they were either confronted by police for begging or were picked up while begging. It was quite revealing to find out use of hand cart by some people because it not only provides aid to those who are disabled but also saves them from being picked up. Begging using hand cart is a symbolic of disability and in such situations police also lets go off those people.

Figure 7 below represents a cyclical depiction of certain causal factors of begging by people affected with leprosy which should be kept in mind while looking at interface of begging and leprosy.

Figure 7 Cyclical depiction of causal factors of begging by people affected with leprosy



Study clearly reveals that begging is a process which should be viewed in the realm of a web of causal factors. As suggested by existing literature (Kumar.A and Anbalagan.M 1983; Vasundhara MK, Siddalingappa AS, Srinivasan BS 1983; Daniel JR, Maniar JK, Ganpati R 1984; Krishnamurty KV and Rao SP 1990) begging is one of the social consequences of leprosy which plays a crucial role in social experience of the disease. Sustained begging is an outcome of reconciliation and unwilling acceptance of situations of shame and indignity over many years (Kaur H and van Brackel W 2002b) which was clearly found out from the field as well. It's not like people affected with leprosy have accepted begging as a sole means of earning but they have no other viable option either.

7.2.2 INTERFACE BETWEEN GENDER AND LEPROSY

There is some amount of literature in leprosy discourse with which findings from the present study can be corroborated with. There is a genre of literature although in very minority which clearly shows gendered connotations in different experiences of leprosy affected men and women (Rao.S et al 1996, Vlassoff.C, Khot.S and Rao.S 1996). Manifestations of existing gender inequalities has been documented in terms if impacting timely case detection, treatment adherence and reversal reactions among leprosy patients and especially for women (Le Grand A 1997). Gender disadvantages of varied nature and dimensions are created in mental, physiological, socio-economic spheres of life and considering developing countries this becomes even more critical where men and women have different socially ascribed status (Naik SS, Hambarde PS, Desai AN 1991; Kaur.H and Ramesh.V 1994; Le Grand.A 1997; Barrett.R 2005; Try.L 2006; Varkevisser CM et al 2009). Amidst these situations women are at multiple levels of vulnerability (Ulrich.M et al 1993; Rao.S et al 1996; Morrison.A 2000) which is important to be factored in. There have been studies which have clearly reported similar findings like from current study where in men were more likely to divorce their spouses if they became ill, and to remarry (Awofeso.N 1995, Rao et.al. 1996) or to get a healthy partner. Impact of leprosy on social experiences of women has been also documented by few (Rao.S et al 1996, Zodpey S, Teary R, Salodkar A 2000). Severity of the disease among women during pregnancy and lactation also finds mention in the literature (Duncan ME, Pearson JM, Rees RJ 1981; TDR News 1997; Barrett.R 2005, Duncan.Elizabeth **in** Nunzi.E and Massone.C 2012). But a sound gendered analysis of issue is something which is in scarcity in present body of literature in leprosy discourse.

Tolhurst et al (2002;137) had given a framework (see figure 8) to analyse gender inequities in infectious diseases (including leprosy) in developing countries. According to them, gender inequities should be seen under three main headings:

- Vulnerability to infection taking into account sex differences in risk of infection,
- Access to healthcare and differential responses of men and women to ill health in terms of service utilisations, delays in seeking care **and**
- Burdens of ill health in terms of impact of the disease on men and women.

These in turn are determined by access to and control over resources, defining of gender roles and activities in a particular context, gender norms and identities, decision making power and social consequences of the diseases onto lives of men and women. And clearly as discussed above, field realities and observations strongly present these situations.

Figure 8 Framework to analyse gender inequities in infectious diseases (including leprosy) in developing countries

Vulnerability to infection: ***Sex differences in risk of infection***

- Gender roles and activities
- Access to and control over resources
- Gender norms and identities

Access to healthcare: How do men and women respond to ill health: ***Service utilisations and delays in seeking care***

- Access to and control over resources
- Gender roles and activities
- Decision making power
- Gender norms and identites

Burdens of ill health: What is the impact of disease on men and women?

- Social Consequences
- Labour Burdens

Source: Tolhurst et.al. (2002; 137)

Having said that, it was found out from the present study that leprosy affects men and women in very different ways. This differential impact is crucial in the shaping of a distinct social and physiological experience of the disease among affected individuals. An understanding derived from recognition of gendered nature of these experiences is very much essential. Gender differences are clearly visible at two levels in the lives of men and women affected with leprosy: treatment seeking and addressal of initial signs/symptoms and entire social experience of the disease including social stigma. By saying that one is not at implying that social stigma is intense for one sex over another, rather approach is to capture 'what and how' of each one's unique experience with a gendered understanding.

What is important to realise here is that although some aspects of experiences of men and women in relation with leprosy have been documented in existing literature but very often it either becomes a comparative between men and women or experiences of women are solely highlighted. Present work attempts to take this existing understanding one step ahead by exploring, understanding and analysing actual life experiences of both men and women affected with leprosy with a gender lens because each one's experience is distinct and crucial. Moreover, this understanding does not exist in vaccum either. It is linked with various other life events of people affected with leprosy and gives rise to a continuing kind of life experience. Following paragraphs present a brief overview of findings from the study in relation with men and women affected with leprosy.

Division of work has been such that irrespective of women's health, domestic household chores are solely her responsibility. Female participants reported about certain instances where they had burnt their hand while cooking and could not make out either because of anaesthetic hand. With no digits in both hands it is extremely difficult to do even simplest of simple tasks like burning of stove or cutting vegetables or wearing socks or holding bucket/utensils etc. It is not easy for men either. The way social roles are defined men it is expected out of them to be bread earners of the household irrespective of the state of their health condition. All four male participants had migrated in search of a livelihood to Delhi coupled with other reasons. For one of the participants sole reason was search of a livelihood option in Delhi because there was nothing which could engage him constructively in his native, although family support was there for him. Manual physical labour is very difficult for them to accomplish because of physical wear and tear and repeated ulceration. One of the colony residents had shared about his experience of driving cycle rickshaw for some time but he had to eventually quit from it because of ulceration and severe wounds he repeatedly kept getting.

All the female participants (except for **De**) reported increased severity of the disease after marriage. At the time of marriage they just had some signs/symptoms which were either ignored or concealed. But post marriage especially during and after pregnancy disease took the worst form for them. It is important to understand multiple vulnerabilities created in a woman's life because of the disease. Understanding of woman's health in totality is very much essential and not just attention to her individual ailments. This kind of physical state tremendously impacted her emotional well being also but it is seldom heard and understood.

It is also worth noting, role of patriarchy in shaping of gender relations and people affected with leprosy are no exception. Among the research participants, all the women were married to a leprosy affected men only. While for men, situations are different. Except for one participant, all of them have healthy wife. This is a general reality in this colony and even in other colonies too which I visited. This is important to be understood with a gender lens. While for leprosy affected man still there exist a choice of marrying a healthy woman or to conceal his signs/symptoms in order to get married to a healthy woman, but for women who are affected with leprosy there is no such choice. Because of the societal norm, women affected with leprosy have to get married and with no choice except to get married with a man who is also affected with leprosy. Even in the way colony functioned, patriarchal set up was clearly evident. None of the women were allowed to participate or have any kind of say in any of the colony meetings. It was male folk who decided and acted. Across the research participants and even at a general level in the colony, there was a considerable age gap between husband and wife. Most of the women were much younger to their male counterparts. In one case (**MuS**), age difference was as much as 30 years. Even while begging, man do not prefer to sit in hand cart if a woman is along with them. Rather woman is asked to sit. As revealed by the participants, this resistance is because of the fact that it is a shameful act for a man to sit in hand cart when a woman is with him. In a nutshell, disease affects not only possibilities of marriage but also various other conditionalities associated with entire institution itself. Amidst all this, women are affected very crucially mediated through existing nature of patriarchal gender relations. But suffering of men is also equally painful but in different ways.

It is very important to consciously pay attention to vulnerabilities created in the lives of people affected with leprosy and the distinct nature of the same among men and women. Women are more at the receiving end. There are multiple axes of vulnerabilities which are created for her not only because of caste and class but also because of the very existence of the disease, deformities and disability, marital status (widowed or single).

This is additionally complicated by literacy status, place of residence, cultural context etc.

Gender dimension exists in phenomenon of migration too. In the colony, including female research participants, none of the women migrated singly. It was impossible for them to leave their native alone in spite of tough life conditions. All of them had come here along with their husband or in certain cases came singly with reference from people back home in order to get married to a man. While in the case of men, this was not the case. All had left their native either singly or with some friend whom they met in leprosy hospital or colony in their native. Delay in treatment in the case of women especially because on denial or concealment will be discussed in-depth in Section 7.3.1. It is important to realise here that decision making power for resorting to treatment has been seldom in her hands. Among all the four women participants, final decision to report to a health practitioner (formal and informal) was made either by their family members or husband.

In the field, non verbal gestures also enabled to understand complexity of gender relations. Men were certainly more spontaneous in sharing and could articulate well. While with women it took a very long time to actually convince and facilitate them to share about their lives. Even while speaking they were not as expressive and much of their sharing's were just followed by a long pause or complete silence. This kind of behaviour is certainly an outcome of social conditioning where men are taught to be more expressive and articulate about their pain and suffering where as for women it is just accepted with silence as a part of life. This was very clearly evident in the field.

7.2.3 SOCIAL DETERMINANTS OF HEALTH AND LEPROSY

Leprosy is one of the sixteen neglected tropical diseases which are also known as 'diseases of poverty'. If looked at medically, leprosy is a result of an infection with a bacterium *M.leprae*. But, if viewed socially, it is a manifestation of social conditions of living and determinants of health which are socially ingrained. And thus, the kind of approach used in tackling the disease also depends on the kind of lens which is used to look at disease causation. Daily conditions of living- the circumstances in which people are born, grow, live, work and age, impact overall quality of human life and their health outcomes in a major way. Inequitable conditions of daily living and inequities in health greatly impact marginalized sections of the population. In such a situation, caste, class, gender, religion and ethnicity play an important role in impacting health of the people in certain ways. There are a wide range of social determinants of health like water and sanitation, housing, education, gender, socio-cultural factors, poverty etc which directly or indirectly impact health of people living with leprosy.

As evident from the literature review, lower socio-economic life conditions have been known to increase vulnerability to acquiring leprosy infection and resultant consequences (Rao KV 1992, Ghimire M 2002, Withington SG et.al. 2003, Duarte MT, Ayres JA, Simonetti JP 2007, White.C 2008, Bonney.J 2011). Factors like caste, class, religion and gender do determine and shape intensity of aggravation and how people with the disease will be treated by others. There is multiplicity of factors which needs to be taken into account while looking at health status of people affected with leprosy (Staples.J 2011a, b). Role of caste and its inter-linkages with leprosy have been explored in an Indian context through an epidemiological study done in Chingleput district of Tamil Nadu (Rao KV 1992). A remarkable epidemiological study done by Pontes.K et al (2004) in Brazilian context very clearly show the links between higher incidences of leprosy and higher levels of inequality.

As stated above, in the literature certainly there is an acknowledgement of socio-economic conditions of living impacting health in a crucial manner. But in available literature a more nuanced analysis of the same is missing. Staples.J (2007a) did mention about role of caste, class, gender, religion in shaping and determining health status of people affected with leprosy but it has been left at that level beyond any further deeper investigation. Present study endeavours to factor in this understanding to scale it up one step ahead. Very consciously a mix of participants from different caste-class-religion backgrounds was chosen for the present research study after a social mapping of the colony based on above variables along with few others. Very importantly a need was felt to take into consideration accounts of people's experiences of leprosy in a wider context of socio-economic-cultural conditions of living.

A holistic outlook of viewing broader life experiences of people with social determinants of health framework enables to better understand specific life experiences in relation with leprosy. This is important to keep in consideration because while onset of leprosy violently ruptures one's life processes with a distinct shaping of life trajectory but a very specific focus on the disease alone downplays its inter-connections with other social factors which also play a crucial role in determining health of the people. Findings from the field clearly reflected unfolding of the role played by various social determinants of health in determining and impacting health outcomes of people affected with leprosy. These determinants are more structural in nature and continue to confront lives of people affected on daily basis.

Among eight research participants, all of them belonged to very poor or poor backgrounds. Financially **Hu** has been far better as compared to rest seven because of his job. All of them lived in and still continue to live in poverty afflicted conditions both in Karnataka and Delhi. Before coming to Delhi, all four male participants were either involved with some petty task or were without any employment. After coming to Delhi, to sustain all of them started begging including female participants. Three participants are Muslim, one is Christian and four are Hindu. Among four Hindu participants, all belong to lower caste groups. Two of the male participants belong to SC category and two of the women participants belong to lower caste group (Non-Lingayat) of Karnataka. All of them are either illiterate or with very low level of education except for **Hu** who is 10th pass. There has been certain level of unawareness on account of the same both at the level of their parents and their own self. This background of participants is important to understand that their lower socio-economic status was one of the contributing causal factors in their affliction with the disease and its further worsening. As evident from narratives of research participants, inter-sectionality between caste, class and gender clearly exists in shaping of their health.

One of the participants presented a clear inter-linkage between caste and health where in his affliction with leprosy was attributed to his food eating habits (beef). A 'class variation' was also reflected from participant narratives wherein reference was made to healthy status of higher caste and class people in their natives (they were not afflicted with leprosy and did not used to eat beef). But in cities this distinction has been comparatively less because caste based identities and implication of the same in seeking health care has been comparatively less. It is important to critically understand as it emerged from the field that people affected with leprosy from lower caste-class groups are triply disadvantaged. Affliction with leprosy in itself excludes them from social processes. Additionally, lower economic situation restricts their capacity to seek appropriate care and deal with the situation amicably. As a member of lower caste category, they also face caste-based discrimination and associated stereotypes.

Discrimination and social exclusion which people affected with leprosy from lower caste and class group face cannot be categorized into 'a particular type'. It is manifested within a web of hierarchical social relationships with graded inequalities and shapes social experience of leprosy in a particular way. As shared by participants, caste, class, and religion based distinction does not matter within a leprosy colony. And to the world outside, they seemingly exist as one homogenous category of 'a leper'. But class background and caste affiliation plays a crucial role in the very creation of vulnerability to the disease and its further management by individuals. Biblical philosophy of love, acceptance and care for a person affected with leprosy impacts their lives tremendously irrespective of religion. It was common to hear from colony people irrespective of religion, about Christ's love for 'a leper' as mentioned in Bible and attitude of Christian missionaries towards them both in Karnataka and in Delhi. In fact, three of the four Christian households in the colony had converted to Christianity. Hindu[75] participants shared about religion based discrimination to their leprosy status which they had faced in their native place. In the case of Muslims nothing much was revealed.

Poverty has been chronic in their lives which has restricted their life choices to a great extent. Poor financial status also hindered 'purchase of privatized health care' and treatment seeking both in their native and in Delhi. Work conditions and nature of work, education, and socio-cultural milieu are some other factors which have impacted their life and health in multiple ways at various points in time. Their nature of work which is begging poses them to tougher conditions of work and increased susceptibility to further wear and tear. Leprosy status has in fact fed into their existing socio-economic conditions of living and a more general exclusion from power and economic resources.

In terms of living conditions, leprosy colonies in Delhi are certainly a major exception. Here, because of mass scale advocacy efforts, land entitlement has been given to residents of the colony with construction of proper houses and supply of free electricity and 24*7 free water supplies. Houses are of course with smaller living space. Delhi being country capital also matters in terms of comparatively better living conditions of people affected with leprosy. Pension given by Delhi government is highest in the country (Rs 1800 per month). But, certainly this is not the case in other parts of the

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[75] In Hindu Dharmashastra also discrimination towards people affected with leprosy and their out casting is clearly mentioned.

country. As shared by various field practitioners[76], in other parts of the country, people affected with leprosy have their colonies towards farthest end of the city, with no proper housing, land entitlement and lack of even basic amenities. A close linkage between living conditions of people and disease is certainly known.

Gender also acts as important social determinants of health among people affected with leprosy. This has been already discussed in detail in Section 7.2.2. Role of socio-cultural factors in disease affliction, progression and present health status will be discussed in further section.

A pictorial depiction of relationship between various social determinants of health and leprosy is given below (figure 9).

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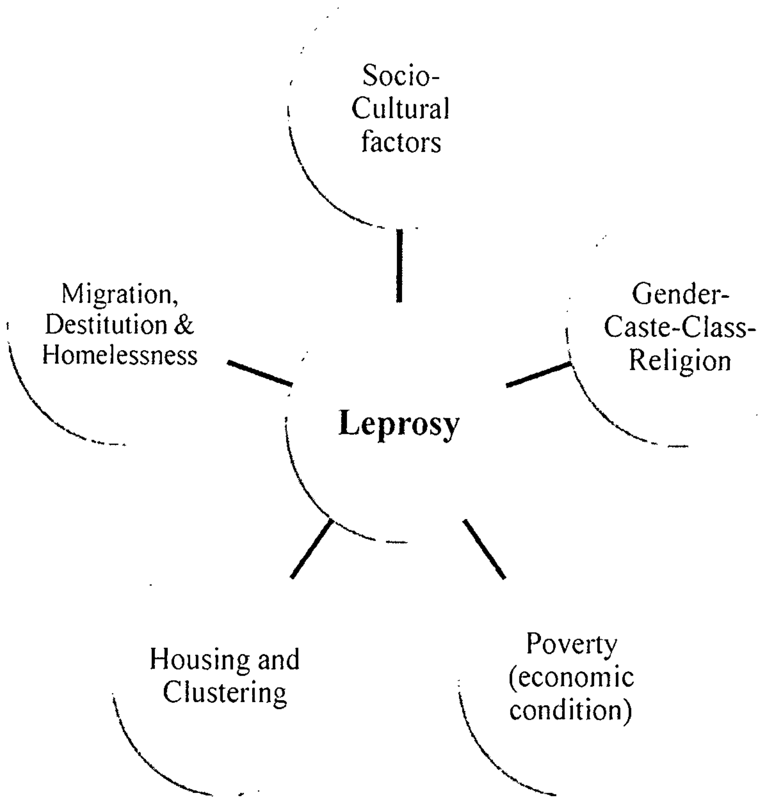
[76] Shared during my meetings with people working with TLM, NLR, in Bihar etc.

Figure 9 Social determinants of health and leprosy



Role played by social determinants of health in creating vulnerabilities to disease may not be visible very directly, rather it requires a more critical understanding looking for inter linkages between various conditions and factors playing role in the lives of people affected. They may not be as clearly visible as *M.lepre* in causing leprosy but certainly they play an important role which needs to be explored in order to understand vulnerabilities of certain sections of the population to the disease. All of them earn a living by begging (except for Hu) in order to sustain daily basis amidst conditions of poverty. There is an inequitable distribution of power, money and resources which also act as conditions of better living and impact health outcomes of people. Embodiment of social hierarchies and graded inequalities is clearly reflected through the present and past health status of people in the field. Thus, it is essential to question why the health of people affected with leprosy is the way it is and looking for its answers in socio-economic-cultural conditions of living is necessary.

7.2.4.1 SOCIAL NETWORK OF PEOPLE AFFECTED WITH LEPROSY AND RELATIONSHIP SHARED WITH SURROUNDING NEIGHBOURHOOD

Radley.A (1994; 176) presented a very apt inter-linkage social support and health status of people both at mental and physical level within a web of social relationships. Relative social isolation and limited or no positive social support in a social network has been detrimental in people's health status. In the domain of health and illness, presence of social support can either improve overall experience or its absence can also lead to worsening of the condition. Psychosocial factors have a crucial role to play in disease etiology. Within social networks there are two components, one is related with links in the network and another is related with level of communication within the same (Kaplan.HB, Cassel.CJ and Gore.S 1977). However, 'social networks' necessarily do not ensure desired social support. It may or may not serve this function (Radley.A 1998, Heaney.AC and Israel.AB *in* Glanz.K, Rimer.KB and Viswanath.K *Ed* 2008). Nature of social ties and their embeddedness within the broader social structure gives rise to notion of social capital (Kawachi and Berkman 2001). Collective efficiency, psychological sense of community, neighborhood cohesion and community competence are four very important constructs that taps into slightly different but yet very overlapping aspects of social capital (Lochner.K, Kawachi.I and Kennedy.BP 1999).

It is crucial to reflect here that in leprosy discourse hardly there is any substantial literature which looks at inter-linkages between social support within social networks and health of people. Although this relationship is well known in the larger health discourse and entire theoretical understanding presented here depends on derivations of the same from larger health arena. Certainly this area needs much more intensive exploration. Present study makes one small attempt to look at the same in the context of leprosy and life experiences of people affected with it. Some of the findings mentioned here do exist at an observational level but a more nuanced understanding of the same is lacking.

Having said that, social network of people affected with leprosy need to be understood at two levels. It emerged from the field work that at one level it is concerned with nature of social ties within the colony or with residents of other leprosy colonies and at another level it is concerned with neighborhood interactions and relationships shared with the family members in their natives. Certainly there is a link between present and past health status of people in the colony with the kind of social networks they have. As known through the literature, social capital connotes influence of society upon individuals (Kritsotakis.G and Gamarnikow.E 2004) and comprises of certain resources and norms that arise from social networks (Freelander 2007). For people affected with leprosy, 'leprosy colony and residents within' comprises of their key social capital within which nature of social ties is of varying nature. But together, as one large group it not only gives sustenance to their collective identity and efficiency but also provides a psychological sense of community which is connected and represented together. Of course, there are variations and binaries within which is obvious for any large setting. In the realm of societal stigma and larger exclusion from social processes, their larger networks with the society are either bare minimum or completely disrupted.

As revealed by all the participants, except for one (**Hu**), admission in leprosy hospital for treatment played the role of a major life turning event. They were admitted either in Bellary leprosy hospital or CL Hospital at Magdi road in Bangalore for treatment. All eight research participants were either accompanied by their relative to the hospital or simply dropped there for treatment or came alone after hearing from somebody. Here, life took a completely different turn. They were not only treated for their ailment but also taken care of. They also found many other people who were also affected with leprosy and with whom they could associate as well because of a common and shared identity. These were the people whom they could call their friends and rely upon. Informal relationships were built which were not by blood relations but based on 'similar disease identity'. People like **Fa** also found her life partner during her stay in leprosy hospital. Participants left leprosy hospital either after finishing the treatment or in between (**Sh**). There was absolutely no returning back for any of them to their native place from leprosy hospital. Dissociation from their own people which was generated during long period of stay in the hospital, stigma and lack of opportunities in their native place were some of the major push factors. All of them headed to leprosy colonies in Delhi about which they were informed while staying in the hospital.

Migration to Delhi was through some known contacts or *via-via* people with a general spread of word. In Delhi, their social network chiefly comprises of people within the colony and people affected with leprosy residing in other colonies of Delhi who are also from Karnataka. Representation is definitely as one large group of people affected with leprosy irrespective of regional belonging or culture. Relationship with people back home in their natives is of varying degrees. Some share good terms with their relatives back home while few others keep it to a bare minimum. All the participants make annual visit to their native either during vacations of their children or during '*moharram*' festival in December. They also keep in touch with people who are residing in leprosy colony of Bellary.

There are no boundaries of caste, class and religion for the residents of leprosy colony. They all share one common identity of 'people affected with leprosy' and represent to the world outside as one large group although there is heterogeneity within. Marriages are also within the network of people affected with leprosy. Even their children who are married do have their spouses with a leprosy background in his/her family. Children prefer to stay either outside the colony or stay with the family in leprosy colony itself because outside the colony cost of living is very high **(Fa, Me, Ya)**.

With the surrounding neighbourhood, residents of this colony share a bare minimum level of relationship. These neighbourhoods also constitute a part of the social network of people affected with leprosy but it has no constructive role to play in their lives. Neighbourhood relationships are driven at both the levels: at the level of people affected with leprosy residing in the colony and at the level of people staying in the larger RK Puram slum outside the colony. Interestingly, nature of this relationship is only of mutually profitable kind where a give and take relationship is shared in certain cases. For example, whatever amount of donation comes to the colony like pulses, wheat grains, rice, oil, sugar etc, if it is in excess it is sold at a price lower then market price to the residents of surrounding slum. It is a profitable activity at both ends because colony residents get to earn money while slum residents get food items at a much lower price. They do not prefer to buy the same from ration shop for various reasons one of them being no ration card. Some of them also come regularly to the colony to fill water from common tap of the colony[77]. It was also seen that blankets or mattresses which are donated in the colony are also sold to a lady who comes to collect it from each house in lieu of some money. Although amount given per blanket or mattress is very less but yet it serves as a means of extra earning for people affected with leprosy in the colony. But at large, leprosy colonies continue to be perceived as 'stigmatized neighbourhoods' by surrounding residents and they prefer to keep their level of communication only to that extent up to which it is profitable for them. Over the years this kind of 'social

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[77] All the leprosy colonies in Delhi have 24*7 free electricity, water supply and proper housing.

ghettoisation' has become an intricate part of their lives which was at one point in time an outcome of certain compulsive conditions. Distinctly polarized world does exist for the people of leprosy colony in terms of 'insider' and 'outsider' (people outside the colony) which is instrumental in defining their social ties and constitutions of their social networks.

7.2.4.2 SHARED IDENTITIES AND COLLECTIVE REPRESENTATION

In the limelight of an understanding presented above, it will be now easier to understand 'shared identities and representations' among people affected with leprosy. Distinctive bodily markings among people affected with leprosy enables not only a sense of a community but also allow mutually shared identities to build up (Staples.J 2011a).

Identity of a *leper/bimar/kodhi/lachar* has gained a prime importance in the lives of people affected with leprosy in relation with recognition by the world outside. In fact their very recognition at large is through these socially constructed and mediated stigmatized identities. Same identity of 'a leper' which became one of the biggest reasons for their expulsion from their native (forced or voluntary) has been a binding force for all of them here in leprosy colony of Delhi (for that matter even other colonies too). They stay in leprosy colony as one large group which is often homogenously represented to outside world. One commonality which is shared by all of them is 'affliction with the disease' and all of them have left their natives or more appropriately compelled to leave. Because of a distinct shaping of life post diagnosis and treatment of leprosy, they identify oneself through 'diseased identity' and relate with one another based on the same.

There are various levels of living with this shared identity. At a personal front it was at the level of initiation of informal contacts in leprosy hospital or leprosy colony elsewhere. This identity is one of the major binding forces for them till today. In cases where both the partners are affected with leprosy there is a mutual understanding about the pain and irony of living with the disease every single day. At a community level, all of them have come together chiefly because of a 'shared common identity' else they all are from very different places and districts in Karnataka. Cultural similarity is one of additional aspects. Leprosy colony is a mini world of their own with their own rules, norms and functioning.

It is also important to understand inter-sectionalities and multiplicity of identities like *leprous beggar, disabled, sinner, diseased* etc which all act in unison to demean 'human life' in a very settled way over time. Their recognition is based on their physical attributes or work choices but not as a human being with 'human identity'. All these identities do intersect at various points in life and give shape to life of people affected with leprosy in a very distinct manner. But undoubtedly, '*leper/kodhi*' is akin with their lives and continues to gain prominence in larger public imagination. It is necessary to realise that these identities are constructed by years of socialization in a distinct way and various social processes which interplay in the lives of people affected with leprosy. One cannot simply do away from it by disguising oneself in a new place or migrating or getting medically cured with MDT.

It was quite revealing to know about an extent to which polarities like *swasthya samaj vs kodhi/bimar samaj* (healthy society vs leper/diseased society) were internalized in the lives of people affected with leprosy. Even the common colony park has been also named as '*Kodhi park*' which only gives a glimpse of in-depth internalization of 'leper's' identity in their lives. Their social segregation and consequent ghettoisation into colonies has existed historically (Buckingham.J 2002) mainly on account of societal beliefs and perceptions which are culturally ingrained. Distinct binaries like *hamare log vs acche log* (our people vs healthy people) are created which have only increased their social distance. There are multiple binaries even within the colony like *widowed vs married, very poor vs poor, panchayat member vs colony resident*, with a distinct power dynamics but yet their representation is as one homogenous group of people to outside world. One must bear in mind here that it is very essential to unpack this 'believed homogeneity' of people affected with leprosy. A deeper scrutiny of the same calls for the distinction as children, women, men and elderly. Indeed identity through which they are widely recognized is same but needs are very different. This kind of understanding certainly becomes very important at planning and intervention level.

7.2.5 MIGRATION AND LEPROSY: UNDERSTANDING INTER-LINKAGES

Migration by families and people affected with leprosy from their natives to another city or region is no new phenomenon (Kaur H and Van Brackel W 2002b, Staples.J 2007a). It was brought to notice as early as 1929 (Rao.B 1930 as cited in Samuel P et al 2012;307). Migration to a new place is accompanied with increased difficulties in diagnosis and communication about illness and treatment on account of circumstances of immigration in combination with social-cultural-linguistic barriers between people affected and healthcare providers (White.C 2011;147). Migration by people affected with leprosy to cities on account of poorer living conditions and no options of better living have been reported by Pontes.K et. al. (2004) in Brazilian context.

In an international context, largely work by White.C (2010, 2011) in Latin American context is available. In much of Indian work as reviewed migration in relation with leprosy was found to be either as a passing reference or as an observation. But there is a paucity of literature with a deeper scrutiny of the same with the perspective of people affected with leprosy and qualitative exploration of the phenomenon. Present study not only reports migration as one of the many inter-linked phenomenons in the context of leprosy but also tries to present a deeper analysis of the same by dwelling upon 'why' of the phenomenon. Some of the work available in relation with migration and leprosy in India is available which reports increase in new case detection rate because of leprosy affected migrants in the city (Chudasam RK 2007, Samuel. P et al 2012). This kind of finding from a research study can be highly problematic and seen as a means of perpetuating the myth of 'migrants as nuisance to cities'.

In the field, all the research participants and other residents of leprosy colony are migrants from various districts of North Karnataka. This empirical work has enabled to understand close linkages between migration, urbanization and leprosy. Insights were also gained about utilization of peripheral urban space (now of course with ever expanding boundaries of cities) by leprosy affected migrant population. These spaces[78] (including of other leprosy colonies in Delhi) used to be outermost corners of the city of Delhi which was used for initial settling down by this disadvantaged and highly stigmatized section of population. As revealed from sharing's of initial settlers of this colony, earlier geographical picture of this area was very different as compared to present times. It was a barren area with few government offices and used by homeless populations as shelter. Overtime with development of the city picture has changed drastically.

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[78] It is important to note that most of these colonies were initially located in city outskirts and next to some *nala* – not very hygienic location with livable conditions. Over time with expanding city boundaries and advocacy efforts picture of leprosy colonies have changed in Delhi. But certainly, picture is very different in other leprosy colonies of the country.

Participants did share about initial difficulties in settling down in a new place and lack of any kind of treatment facilities because of a new place. This also contributed to neglect of existing health conditions.

Research participants shared various reasons for migrating to a city like Delhi which is thousands of kilometres away from their native place. Search of livelihood options, better living conditions and treatment facilities, intense stigma in native place, anonymity of living and marriage have been some of the major reasons.

It should be noted here that although all the research participants have been settled in Delhi for almost two decades or more then that but still they carry a migrant status with not even basic identity or residence proof. Some of them have voter identity cards of their native till today while rest of them have no card only. None of the residents in the colony including research participants have any ration card or below poverty line (BPL) card.

A distinct pattern of migration was also visible upon observing it minutely where in all the male participants had migrated either singly or with their friend. While in the case of women it was'nt alone. All the women had migrated to Delhi after marriage (**Me** to get married) in spite of tougher living conditions in the native place.

7.2.6 LIVELIHOOD AND LIVES OF PEOPLE AFFECTED WITH LEPROSY

Having understood the phenomenon of migration in relation with leprosy, now it will be easier to build an understanding about livelihood options in the lives of people affected with leprosy.

One of the reasons determining people's decision to migrate from Karnataka to Delhi was in search of livelihood options. In their native place they had no option available to earn a living and make their ends meet. Affliction with leprosy was one of the major impediments. At least three of the research participants had to quit from their existing occupation which involved farming, sewing clothes etc (Ya, Fa, Me).

In contrary with their hopes, after reaching Delhi in spite of trying none of them could locate any dignified means of earning. Under situations of despair because of no means of earning all of them were channelled into begging seeing other people affected with leprosy doing the same. It was not easy but there was no option either. Since then begging has been one of the sole source of earning for them. They did try to earn a living in a dignified manner but because of stigma attached and physiological incapacities it was impossible for any of them to work. One of the participants did mention about his attempts to earn a living by driving cycle rickshaw but very soon he had to quit from the same on account of physiological incapacities. Seven men from this colony including one research participants work as sweepers on daily wages with MCD. In the case of women, they either take care of household or go begging to make their ends meet. This finding differs from the one reported by Staples.J (2007a;174, b;168) where in people had migrated from Hyderabad located leprosy colony exclusively for begging to distant cities like Mumbai, Delhi, Kolkata or close by located cities.

As discussed in the section 7.2.1 on begging and leprosy, there is a widely held understanding among people in the mainstream society at large that people affected with leprosy do not want to work and like begging in spite of being given options. But findings from this study completely differ from this myth. People do want to work with dignity in spite of affected with leprosy. It is the conditions at large both at personal and societal level which obstruct their means of livelihood and left in a situation where there is no option except to beg if one has to survive. Although we may call 'begging' as a livelihood or occupation of people affected but they themselves never accept it as their livelihood. It is only a means of survival in sheer desperation which has only got routinized over the years amidst compulsive situations. It clearly emerged from the field that there is a desire deep down among each one of them to earn a living with dignity even today but situations are absolutely not permissive. Life has to continue in any case with family responsibilities. One cannot sit home and has to earn. Moreover, state welfare mechanisms are also inadequate. As a result one is compelled to beg in spite of not wanting to do the same. As shared by participants begging is not at all an easy means to earn because of intensive physical labour required and exertion but yet they have to because there is no other choice either.

7.3 HEALTH EXPERIENCES OF PEOPLE AFFECTED WITH LEPROSY: A DISCUSSION

7.3.1 HEALTH SERVICE SYSTEM AND PEOPLE AFFECTED WITH LEPROSY

Delay among people affected with leprosy[79] between onset of symptoms and the start of treatment has been well known and documented in literature across the globe. Reducing this delay by early detection and timely reporting is one of an important means in curbing disability which follows subsequently in an absence of treatment[80].

A case control study done in Ethiopia by Bekri.W et al (1998) revealed that high rates of disability in all cases was because of greater delay in starting treatment and associated with high social stigma and use of traditional medicines for longer durations without any health outcomes. Total delay was divided into three components: delay between the onset of symptoms and the first act of health seeking behaviour, delay between the first action and the first visit to a recognized clinic and the delay between the first authentic clinic visit and actual start of treatment which was important for those people whose delay was due to problems within the health services. Nicholls PG et al (2005) identified factors contributing to delay in diagnosis and initiation of treatment for leprosy. It was identified that the most important contributor to delay in the first action for seeking treatment was because of simple monitoring or ignoring first signs/symptoms. A mean delay of 18 months was reported. People were found to have made multiple visits to traditional medicine practitioners adding up to mean delay.

Study done among out patients in a clinic of Nepal by Robertson LM, Nicholls PG and Butlin R (2000) clearly brought to fore that delayed reporting of leprosy signs and symptoms is a major risk factor for disability among people affected with it but this delay is an outcome of a complex interaction between physical, social, economic and psychological factors. A significant relationship was reported between the delay in reporting of symptoms and age, rural environment, leprosy classification, walking time to health facility, social stigma and inappropriate first action. Lack of education was not found to be very significant in delayed reporting. Initial lack of awareness and an

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[79] Leprosy is a leading cause of non traumatic peripheral neuropathies worldwide (Ridley DS 1969 as cited in Rosenberg NR, Faber WR and Vermeulen M 2003)

[80] Although study by Rosenberg NR, Faber WR and Vermeulen M (2003) also reported about unexplained delayed nerve impairment (neuropathy) among people who developed it after treatment. Two groups were identified one with acute multiple mononeuropathy and another with progressive multiple mononeuropathy.

inappropriate first action were the key contributors in delayed reporting and disease progression. Study in China by Zhang.F et al (2009) reported a similar aspect wherein delay in diagnosis of leprosy was found very common and associated with nerve impairment leading to disability. Total mean delay of 50.18 months was reported. In spite of appearance of signs and symptoms like numbness, tingling, patches first health seeking action was quite delayed. Ignorance about illness was found to be the main contributor to this delay. Souza Da'Silva.C and Bacha.T.J (2003) through their study in Brazil identified misdiagnoses and unawareness about the disease as main factors posing as obstacles in early diagnosis of leprosy.

Study by Renita.L et al (2010;299,304) in India about health care utilization pattern of among leprosy patients reveals that patient related and health care system related delays both contributed in overall high percentage of delay in seeking treatment. Very importantly it was also reported that 78.6% (22/28) of patients required care after cure in spite of completing the treatment. Substantial time lag between case registration and commencement of treatment in a leprosy control unit of Tamil Nadu has been reported which was longer in Paucibacilliary (PB) cases, women and children (Murthy PK et al 1992). Time lag in seeking treatment for leprosy signs and symptoms has been well known among women (Mull et al 1989; Kopparty, Karup, and Sivaram 1995; Rao et al 1996; TDR News 1997; Andayi FM, Ghenga WJ and Orege PA 1998; Peters ES and Eshiet AL 2002; Barrett.R 2005). As already known, this delay is very importantly shaped by socio-cultural context and economic factors among people affected with leprosy and for women this is very well pronounced across societies.

In South Asian context, a range of multiple indigenous systems of medicine along with biomedicine have co-existed (Durkin 1984, Parker 1988, Leslie 1980, Nichter 1989 as cited in Lambert 1996, Kirmayer 2004). Existence of multiple systems of healing and a distinct pattern of resort with hierarchy has been reported in general by various academicians. Work of Nichter.M (1978) in a rural primary health centre zone of South India gives fruitful insights in relation with illness specific pattern of resort among populations and tendency to report to indigenous practitioners at first. Work of Lambert.H (1996, 2012) in relation with medical pluralism and her work with bonesetters in India give important insights corroborate with present empirical study. Her works investigates a form of indigenous therapy that does not fit within the domain of officially recognized categories of Indian medicine but yet is a popular source of informal medical care among people. In a quest of 'authentic expertise' there have been contestations over legitimacy among individual practitioners and hierarchies within it (practitioners and medical traditions) (Lambert.H 1996, 2012). In the domain of health in general, multiple ways of comprehending health of the people with possibilities of choice between different range of practitioners, between consulting or self-reporting have always existed (Cant.S and Sharma.U 1999).

Even in leprosy discourse, it is very essential to understand entire spectrum of informal medical care and non professional expertise as utilized popularly by people. One of these kinds of work is by medical anthropologist Barrett.R (2008) done in Varanasi with indigenous practitioners (Aghori) in the context treatment of socially stigmatized diseases like leprosy. But apart from this not much of literature is present especially in relation with treatment of leprosy- systems of medicine, pattern of resort among people affected and what determines those choices. Present study attempts to build upon this understanding drawing from other work in the context of health and healing. Nicholls PG, Wiens C and Smith WCS (2003;198) very appropriately wrote

> *"Delay in presentation of sign and symptoms is linked to traditional beliefs, lack of awareness of the early symptoms of leprosy, stigma, seeking help from natural healers, and to interactions with the health services. Traditional beliefs diminish the importance of the early symptoms of leprosy. Stigma has an impact on decisions to seek help. Natural healers have maintained their traditional status in society; but their preferred treatments for leprosy are ineffective. Only rarely do natural healers refer to the health services. Once presented to the health services, some individuals affected by leprosy experienced lengthy delays in diagnosis and start of treatment".*

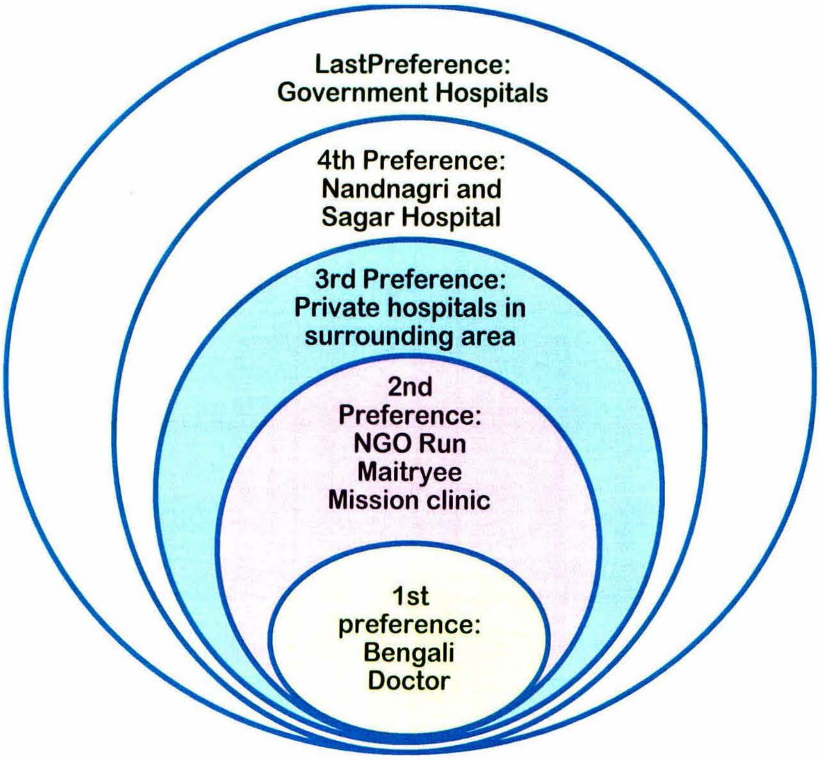
Thus, once can see that various aspects of treatment seeking behaviour, delays and consequent progression of the disease have been reported across various settings for both the sexes. Observations have been also made in relation with treatment seeking through indigenous medicine practitioners and hopping from one system of medicine and practitioner to other. This research study endeavours to build upon this existing understanding in relation with leprosy and explore additional dimensions of the same through life histories of research participants.

Delay in seeking right treatment because of various reasons has drastically impacted the progression of untreated disease and subsequent manifestation in the form of disability. Because of anticipated stigma in relation with 'one's diagnosis of leprosy' there have been instances where people attempted to either deny or conceal initial signs/symptoms till a point when it was no longer possible to hide the same because of visible manifestations. In certain cases, people were unaware also initially in terms of how to deal with appearance of signs/symptoms. Treatment was sought at a much later stage when disease was beyond proportions. Cultural belief and practices also affected delay in treatment seeking. It clearly emerged from the narratives of research participants that some of them made attempts to get treated by indigenous practioners in a hope to get cured. But this was all in vain. Here it is important to note that in the case of women situation was even worse. Their complaints about initial signs and symptoms were either ignored by family members or attempts were made to conceal the same else it would have caused trouble in getting them married which is socially expected. All the participants showed first signs and symptoms in an age group ranging from 7-15 years. And there was a time lag of many years, at times 8-9 years, in seeking appropriate treatment at a health facility. Disabilities among all eight participants were completely preventable if right treatment would have been sought at the right time.

A distinct '*pattern of resort*' has emerged in treatment seeking behaviour of all the research participants. A wider health culture (term coined by Banerji.D 1972;2261,1975;70, 1982) of the community did play an influential role in governing and shaping their choices and decisions. People affected with leprosy have tried to seek treatment from a range of formal and informal practioners in a hope to get cured. This was driven by larger health beliefs and culture of the community as well. Within this pattern of resort there has been a distinct level of hierarchy as well. This implies advice was sought from certain kind of practioners first and later from others. It was found out that, while in Karnataka as well as in Delhi, people affected with leprosy preferred going to indigenous/informal practioners over biomedical practioners. In their native, they sought treatment first from '*vaidya/hakim/jhaad phook wala*' and then later from biomedical doctor. In Delhi, all of them prefer going to Bengali Doctor first who is located in a close by slum. If situations are beyond his control he refers people outside. A charitable clinic run by a voluntary organization is their next preference. People also resort to The Leprosy Mission India (TLM) and Missionaries of Charity run hospital located in Shahdara. Private practitioners in surrounding RK Puram area come 3rd in their order of reference. Government hospitals and doctors come in to picture towards the end. Preference for Bengali doctor in Delhi is driven by many factors like rapport, his availability and flexibility, affordability, efficaciousness and quick relief from his treatment, close by location, people's firm belief in him and his complete acceptance of people affected with leprosy without any biases or prejudices. Although private practitioners behave well with them but treatment is highly unaffordable for them. There have been instances among eight participants where they had to take loan from grocery store lady (within the colony) in order to get treated in private for even minor ailments. Sharing was also made by people in relation with a shift from private to government hospital while seeking treatment in their native. This step was taken mainly after getting exhausted with money.

Variety of health practitioners to whom people affected with leprosy resort to in Delhi can be represented diagrammatically in their order of preference (see the figure 10). This order of preference is based on field interviews and interactions with other colony residents affected with leprosy.

Figure 10 Hierarchy in Pattern of resort by people affected with leprosy from the field area



There are many reasons for not preferring government hospitals and doctors very easily. This is in spite of close proximity of Safdurjung hospital and AIIMS at a distance of 5Kms. Long waiting time and queue, attitude of health staff including doctors, repeated visitations and lack of an effective rapport are to name a few. Moreover, because of their physical condition they are unable to take in much of physical exertion which in fact affects them while seeking treatment from Government hospitals. In extreme situations, people resort to a dispensary in Motibagh which is close by. In this entire process of doctor shopping and jump from one system of medicine to another and one practioner to other, physical and mental suffering multiplies manifold with sheer waste of money and time.

It is very important to note here that long waiting time and queue because of skewed doctor patient ratio in government settings like AIIMS, Safdurjung also leads to loss of one day earning by people affected who make a visit. Treatment is not over just in one visit and in a short duration. Repeated visits imply loss of entire day's wage every time and it means a lot in the case of people affected with leprosy. It implies not being able to go to beg for one entire day with additional expenses incurred in making a visit to health setting. Similar kind of finding was documented by Zubrigg.S (1991) in her seminal work 'Rakku Story'.

As stated above, health practitioner's relationship with people who come to seek treatment is one of an important factor in deciding their probability of returning back in future or continuing with the treatment. Peer group sharing also impacts their choices. Like in the case of this colony, there is a general word among colony residents and people residing in the slum about good behaviour of Bengali doctor which also makes him a popular choice among people. Whereas in the case of government hospitals, there have been instances of stigma, callous behaviour which played an active role in distancing people from government health services.

7.3.2 BIOMEDICINE AND LEPROSY

In the popular leprosy discourse, an understanding based on biomedical cure by MDT, reconstructive surgeries etc are very popular. This emphasis is laid by all active players in the field of leprosy, government, international organizations, international bodies, national organizations, field practitioners etc. What is important to realise here is that this emphasis is indeed required but not sufficient in itself either. To understand lives of people affected with leprosy in totality it is very important to pay attention to interface between biomedicine and leprosy and implications of the same in the lives of people affected with leprosy. This has very clearly emerged from the field.

D Banerji, as cited in Rao KV (1992; 381), had once stated that "*Leprosy is a particularly devastating disease, devastating not only in terms of the degree of damage it causes to any individual, but it is also devastating in the sense that the person has to live for decades together with a physically and mentally devastated life. It also has devastating impact on his family life and his life within the larger community*". But this is a much marginalized understanding in mainstream leprosy discourse and literature available. Present study makes one humble attempt to reiterate the same understanding articulated above which yet needs to be recognized at practice and planning level.

Treatment with MDT or Dapsone (in some cases) has certainly cured them from leprosy infection. But in the case of all eight research participants this medical treatment was sought at an advanced stage of leprosy when deformity had already appeared and it was irreversible. Medicines did render them non-infectious but did not cater to manifestations of leprosy which are lifelong. Existing deformities worsened even more because of repeated ulceration in anaesthetic limbs. Thus, in spite of medically cured all the research participants were dehabilitated from their life processes in a very slow and settled manner. Onset of leprosy only acted as a trigger to a cascade of inter-linked life events and contributed in shaping of present and past life of people affected with leprosy.

An understanding articulated here has emerged very clearly from the field across all eight research participants and even through general community interactions. It is duly acknowledged that cure with MDT certainly curbs the disease at an initial stage and contributes to decline in prevalence rate of leprosy. But care after cure component is actually missing to a large extent which becomes a major factor for majority of these people who are cured to get pushed in to begging and migrate to a new place. Irrespective of medically defined status, socially they continue to live with stigma and an identity of a leper.

Research participants also reported about that while a visit to biomedical health practitioner is made he/she only looks for visible signs/symptoms of ailment/condition they report and certain times simple sends them without even trying to listen and understand what their experience is like. This mechanical way of dealing leaves them dissatisfied. While on the contrary, Bengali doctor in Delhi and indigenous practitioners in their native did used to hear them very patiently catering not only to their disease but also to their intense suffering.

Even in national leprosy programme this extensive thrust has existed which stands out quite differently from the thrust laid on socio-economic and cultural aspects of the disease. It was clearly reflected from participant's narratives that '*bimari*/disease' was seen separate from various complications related with the disease. This disjuncture between clinical understanding about leprosy and socio-economic-cultural aspects of the disease has only contributed in worsening of individual and community experience of the disease. Need of the hour is to bring balanced convergence between the two rather than overlooking one at the cost of other as discussed above.

7.3.3 DISEASE, ILLNESS AND SUFFERING

A very crucial focus in this empirical work is to carefully capture narratives of pain and illness of all the research participants embedded within their overall life experiences.

Indeed there is a great amount of literature in relation with illness, pathologized bodies and people's experiences but in leprosy discourse this kind of work is seldom encountered.

Capturing narratives about pathologized body by individuals are a way of taking into account how they experience their illness and what kind of meanings do they create or discover in relation with illness. In the case of stigmatized conditions like leprosy, disease becomes a key metaphor in the lives of those affected with it (Sontag.S 1990). Kleinman.A (1988; xiii) wrote very appropriately

> "*Illness narratives edify us about how life problems are created, controlled, made meaningful. They also tell us about the way cultural values and social relations shape how we perceive and monitor our bodies, label and categorize bodily symptoms, interpret complaints in the particular context of our life situation; we express our distress through bodily idioms that are both peculiar to distinctive cultural worlds and constrained by our shared human condition.*"

These narratives if understood and analysed appropriately can be very insightful in terms of revealing actual experience of illness in the lives of those who suffer from it, and channelizing that experience for therapeutic value (Kleinman.A 1988). Frank.A (1995), conceptualized people telling stories about their illness as active players whose story emanates from their real experience as 'wounded story tellers'. Here in the context of research, people affected with leprosy who narrated about their entire life stories including their narratives of pain and illness are 'wounded storytellers'. Their wounds and episodes of pain have been able to impart a narrative power to them. Frank.A (1995;xi) very appropriately writes that "*ill person who turns illness into story transforms fate into experience*" which has been an attempt made through present empirical work as well. But indeed this 'narration' does not come easily because ill people are wounded not just in body but in voice too. They have been often silenced through illness and treatment over the years which need to be articulated (Frank.A 1995).

Bury.M (1997) had outlined a 'socio-medical model of disabling illnesses' (like leprosy). He distinguished between two types of meanings associated with having a chronic illness or 'disability': first as '*consequence*', which refers to impact of illness on person's everyday roles and relationships; and second as '*significance*', which implies cultural meanings and symbolic significance associated with specific disease conditions. '*Consequence*' shapes social experience of the disease and impacts 'normal life conditions' of those affected. This has been exactly found in the case of research participants as well where affliction with leprosy not only hugely impacted their daily routine activities in varied ways but also a distinct shaping of their social relationships also took place. *Significance* of the disease has been reflected through a distinct stigmatized representation of people affected with leprosy which has been upheld since time immemorial till today.

As discussed in Section 7.4.1 disease connotes a medical condition with distinct physiological symptoms in the purview of biomedicine where as illness connotes suffering more at a personal level in experiential terms. Suffering exists in all the cases which is not only physiological but also mental and emotional. And in the case of socially stigmatized diseases like leprosy suffering takes an intense form. It was found out from the field that complete well-being is not just medically designated non-infectious state. Well-being implies various connotations and is more of a personalized experience at the level of an individual.

As mentioned before, participants reported about lifelong manifestations of leprosy like neuritis, ulceration, lagophthalomous eyes in spite of MDT treatment. For them understanding existed at the level of complete healing after taking MDT. But this was completely opposite to what they continued to experience. All the participants reported about resorting to the right treatment when suffering was beyond the threshold of tolerance and took its worst form. There have been continued episodes of intense pain which are seldom paid attention. Chronicity of pain is a hard to accept reality for most. This has fed to some extent to their disillusionment with biomedicine because in spite of taking treatment for leprosy their suffering has not eased in any way. Narratives about pain emerged across the participants so often which are seldom recognized when they visit any biomedical practitioner.

Intensity of acute pain has also lead to substance abuse among people affected with leprosy including some of the research participants **(Go,Fa,De, Ya,MuS)**. Both men and women shared about consuming *paan* or tobacco or country liquor in order to suppress pain temporarily and fall asleep. These substances are also consumed to curb hunger by some.

In addition to leprosy, there is suffering because of associated co-morbidities like TB, Diabetes, High BP, Asthma, Liver cirrhosis, Back-pain, Arthritis etc. Because of stigma attached with their condition, they find difficult to seek treatment even in relation with other health conditions which is only silenced within their physiologically and emotionally pained self over time. Episodes of intense pain are part of their everyday life schedule. Pain has been a chief metaphor in their illness histories, in their loss of close people and social status (Barrett.R 2005;224).

Participants also expressed an embodiment of their healthy self through me by using words and phrased like *tumhare/you, tumhare jaise haath/like your hands* etc. This was also indicative of their bodily dissociation and thus neglect towards injuries and ulceration to an extent of severity. Impact of social stigma was also crucial in shaping of such kind of behaviour at an individual level. There were many verbal and non verbal expressions which clearly signified a certain degree of self mortification among them. Even during initial field visits there were repeated attempts by participants to hide their disfigured bodies as far as possible. Work of Barrett.R (2005;216) highlights a similar finding wherein as an outcome of mortification processes over many years, people affected with leprosy actually start embodying various societal prejudices which have actually exacerbated their condition in the first place. He very appropriately categorised physical expression of destructive processes in relation with social stigma of leprosy: strategies of concealment which lead to further disease progression, bodily dissociation and self neglect because of internalized stigma and intentional seeking of injuries by certain people amidst conditions of acute poverty. But there is not very extensive list of literature in this context.

Physiologically leprosy also poses a huge impediment in doing manual labour. This also contributes in restricting their earning choices and a lot of them are eventually siphoned off into beggary.

Thus, it is very essential to explore and understand various aspects associated with overall experience of leprosy including physiological, mental and emotional aspects in the lives of those affected. Over the years they have also developed their own unique ways to struggle and cope with the same on everyday basis. It might be in any form like tolerating, self neglect, mental and physiological dissociation, isolation, concealment etc.

7.4 STIGMA, DIGNITY AND LIVES OF PEOPLE AFFECTED WITH LEPROSY

It was realised during the course of the present study that an understanding based on concepts of stigma and dignity is very much crucial to this work as a public health practitioner. This is in order to recognize, understand and address various processes of denial and discrimination in the lives of people affected with leprosy. So if one says that people affected with leprosy do not come for treatment or quit after starting the treatment or do not take care of themselves or continue to beg in spite of trying to rehabilitate them- answer lies in understanding their experiences of stigma and conceptualization of dignity by them. Overtime, there are various episodes of routinized violence in different forms wherein they actually cease to see themselves as a 'human being' and 'respectable citizen'. Stigma has been akin with their lives and manifested in various forms with very grave impacts. 'Leprosy illness' has become a greatest metaphor in their lives accompanied with multiple forms of identities with an undignified and stigmatized self. This overshadows their entire human existence in fact making them doubt after a while that are they really human beings?

In leprosy discourse, there is endless amount of literature available in relation with stigma using qualitative, quantitative or mixed method designs. Some have devised stigma scale to measure stigma in the lives of those affected with leprosy. But there is handful of literature which actually emphasises the need of looking at context of stigma and viewing it at three levels of causes, forms and impacts (Staples.J 2007a, b; 2011 a,b; Harris.K 2011; Poestges.H 2011;Kazzeem.O and Adegun.T 2011). It is the special edition of Leprosy review journal in 2011 on stigma which actually gives a much nuanced understanding of stigma through a collection of a range of carefully written articles. But in relation with dignity, there is hardly any literature in leprosy discourse which attempts to study conceptualization of dignity or notions of the same by people affected with leprosy. Dignity has been of course used as a term but a deeper analysis and exploration of the same is absent. Present work attempts to bring in this understanding in academic work in relation with leprosy which has important bearing on field level practice and planning level too. This also opens up areas for future research.

Now we begin with a brief overview of literature which is relevant to present discussion in relation with experiences of stigma and conceptualization of dignity by people affected with leprosy.

In relation with dignity a deliberate attempt has been made to look at the way dignity is actually conceptualized, reflections of which are seen in parallel with conceptualization of dignity by people affected with leprosy. Much of this exists in the context of philosophical foundations of bioethics.

One must realise that dignity acts not only as a 'condition' but also as an 'enabling force'. A life with dignity where one is regarded as complete and equal human hood would be closely related to one's sense of individual, collective and social well being and life with denial of dignity in social and material realms would mean a denial of health itself (Despnade.M 2006). As given in existing literature, conceptualization of dignity exists at two levels: source and content (Seifert.J 1997).

Kantian notion of dignity implies that every human being should be treated as an end, not as means. Notion of moral capacity of individuals and people is underlying here. It is essential to respect free choices of person and their right to self determination. There is an emphasis on 'individual will' giving centrality to individualist ethic - priority to individual choice and autonomy in social, political and legal environments. Here the concept gets linked with 'freedom, choice, self-determination' (Deshpande.M 2006). This notion of dignity derives from a conception which is believed to be 'acquired'. It lies in awakened conscious life and actions (intentional or free) with actualization of an individual's potentialities and shaping of personality.

There is another notion of dignity whose roots are ontological in nature (Kolnai.A 1976; Zúñiga.G 2003).This signifies respect for person's life and integrity: his/her very existence as a human being. Root of person's essential dignity is in his/her unique mode of being an individual substance of rational and free nature. Their 'mode of being' precedes actualization of any mental, physical properties and notions of morality.

It is very important to transcend the boundary of 'individual' to an understanding derived from collective sense of dignity and its interpretation at a commune level. Idea of human dignity involves a complex 'notion of the individual' which not only includes recognition of a distinct personal identity, reflecting individual autonomy and responsibility but also embraces a recognition that the individual self is a part of larger collectivities which play a crucial role in creating the meaning of inherent dignity of the person (Schatcher.O 1983).

Having said that now we move on to aspects of stigma relevant to present empirical study which exist in literature.

As evident from literature review, stigma is an ongoing dialectical social process which is very much contextually (socio-economic-cultural-political-historical) ingrained and impacted by nature of social relationships (Harris.K 2011, Staples.J 2011a,,b, White.C 2011).

Emphasis on stigma should not be such that it overlooks other drivers of social exclusion much of which is contextually placed. Parker R and Aggleton P (2003;149), as cited in White.C (2011), clearly articulated that understanding stigma as a process should be such that it is linked with reproduction of inequality and exclusion in society. Preconceived ideas/notions/beliefs lead to stereotyping of 'a particular group of people' and when stereotypes are attached with 'a label', society ceases to see individuals as human being. Individual and groups are reduced to an image in synchronization with stereotypes defined for them. Binary cartesian co-ordinates of 'them vs us', 'healthy vs diseased' are constructed and people are seen within it. This very distinction is the beginning of discrimination and a cascade of other kinds of negative behaviours towards individuals and groups who are stigmatized.

Stigma needs to be unpackaged into its causal factors and consequences rather than using it as one umbrella term (Staples.J 2011a). Appropriateness of the same was revealed from field realities where in stigma did not prevail in the lives of people affected with leprosy in one universal way. There have been causes, forms and varied impacts of the same as revealed from participants sharing. Moreover, taking into account individual and collective notions of stigma is also important to see how it is experienced and manifested at an individual and group level. This calls for a shift away from an understanding dependent on variables of psychology to a more holistic psycho-cultural-social understanding (Harris.K 2011). In the present study an attempt has been made to relate individual notions with community notions in order to see them in totality.

From the field it is revealed quite clearly that there are distinct causes, forms and manifestations of stigma in the lives of people affected with leprosy. For a deeper scrutiny 'stigma' needs to be unpacked rather than using it as one umbrella term. As reflected from the study, there is a direct relationship between natural history of the disease and stigma perceived against people affected with leprosy. As the disease progresses naturally in an absence of treatment, deformities also start appearing because of ulceration and wounds in anaesthetic limbs. Thus the very fear appearance of a patch on body brings in a dreadful picture of 'disfigured deformed body' in the minds of people at large. Fear emanates from here. Moreover, in response to this fear and anticipated repercussions of leprosy there is a tendency to conceal or deny appearance of patch of leprosy on body. This is clearly evident from participant narratives and the discussion in above sections.

Field situations demonstrate importance of a certain context, which is socio-economic-cultural-political-medical in nature, in generating, mediating and perpetuating stigma. Health related stigma on account of leprosy is certainly one form of stigma which exists in the lives of people affected with leprosy but the story does not end with this alone. Leprosy does act as a trigger to many of life events but there has been a certain prior context presented by a mix of factors based on caste, gender, economic situations, educational status etc. It is also very difficult to separate self and enacted stigma which confronts lives of those affected. Both of them play out in unison in impacting lives of people in varying intensities. Stigma is also faced by family members of people affected with leprosy (courtesy stigma)[81] which poses restrictions on their life functioning's as well. As understood from participant sharing's, intensity of stigma has been less in cities including Delhi as compared to their native place in rural areas of Karnataka. But this in no way implies absence of stigma in cities. Status of stigmatized neighbourhoods given to leprosy colonies by surrounding localities, inability to find a dignified means of earning even in a city like Delhi , marrying of children (second generation) within households with leprosy backgrounds only etc are some of the examples which illustrate social stigma displayed even in cities.

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[81] Term coined by Goffman.E (1963) in his seminal work 'Notes on management of spoiled identity'.

Some of the participants also articulated about their experiences of 'iatrogenic stigma' in health settings in various ways which did impact their health service access and utilization. At times it was very covertly expressed but yet it was sufficient enough to hurt their basic human dignity. This was also one of the major reasons for avoidance of government health settings by all of them.

Work in a leprosy colony and interaction with residents also enabled in understanding community level experiences of leprosy. Identity of 'a leper' serves dual purpose in their lives. On one hand side it exposes them to stigmatizing life situations where as on the other hand side it has become one major binding force for leprosy affected people of 'leprosy colony'. These colonies are seen as stigmatized neighbourhood by surrounding residents but for the residents of the colony it is small mini world of their own which is the only place where they receive acceptance and human worth in spite of leprosy. Very name of the colony as 'leprosy colony' bears a connotation of indignity.

Creation of a distinct stigmatized identity of 'a leper' is synonymous to living identity of people affected with which they are recognized all through their lives. People from the field often questioned that why a *diabetic* is not stigmatized while a leper/*kodhi* (as popularly called) is stigmatized? Of course in language discourse there have been shifts in terminology, current one being usage of 'people affected with leprosy'. But in the society usage of the word 'leper or *kodhi*' has historically existed and still continues to be in use which is loaded with intense social stigma.

Impact of stigma is also very crucial which is reflected from a distinct shaping of life experiences of research participants. These are the people who continue to face years of dehumanization, discrimination, humiliation and social exclusion. This has completely deprived them from their 'inherent human dignity'. It wasn't like they never had human dignity or it was never acknowledged. But onset of the disease coupled with existing situations of life and its manifestation in various forms did disrupt it immensely. A sense of dignified self is completely disrupted but yet deep down their hearts there is an unseen unspoken plea for self respect and a right to live with dignity. Violence (not necessarily physical) has been akin with their lives which has is routinized over the years. There is an unwilling acceptance and compromise with the same in order to cope with life conditions. Indignity has been so deeply woven with their life events and processes that it has been impossible for all the research participants to actually think of moments when they were actually treated as human beings. Indignity of begging has clearly emerged through their narratives. Indignity is akin with their almost every life event but for the participants it has only got settled down painfully deep down their hearts. Field observations gave an opportunity to closely see indignity playing out even during donation activities like food distribution. Donation and charity activities do help in meeting their material needs to an extent but their emotional needs are never ever met. Deprivation is not only material but also psychological.

It was found out that research participants had a unique notion about their dignity. It did vary from person to person but essentially crux was same. There sharing's enabled in defining certain key components of dignity like work, food, health, education for children, living conditions etc. For them very gesture of touch, willingness to talk, sitting with them etc signified person's acceptance of their 'diseased self'. For them this was their dignity. Work by Deshpande.M (2006;65) also enlisted some of the similar components of dignity as articulated by Dalit women of Raichur district, Karnataka.

Participant narratives, field observations and interactions clearly demonstrate a bitter reality of the life of people affected with leprosy. Ontological origin of dignity is seldom recognized. Their 'human hood' is certainly seen as flawed and of lowest rank because of the very affliction with leprosy. Emphasis is on moral aspect of dignity by defining it as a quality which is acquired. Rebuke expressed as '*heinous leprous beggar*' illustrates the point. Because of poverty, poor living situations and leprosy status – human dignity is just stripped off from them. This is in dire contrast even with the basic principles of human rights and declarations made both nationally and internationally.

Recognition of the vicious nature of the compelling situations in their lives seldom exists. Instead there is a victim blaming where people affected with leprosy are projected as ones who do not want to work, are lazy and want easy money by begging. Recognition of these people is based on certain labels and stereotypes set in societal imagination which is hard to ameliorate with health communication alone. It is more at a psychological level which is expressed behaviourally in many ways.

This field study has enabled in understanding a multi-factorial rootedness of the social experience of leprosy. An understanding gained about life experiences of people affected with leprosy based on concepts of stigma and dignity has also enabled to see their life in totality rather than in a box of leprosy alone. Entire aspect of stigma cannot be merely zeroed down to leprosy alone as it is encountered popularly in the literature. And dignity can never be seen in gradations as a moral quality. It is inherent and inalienable. Conceptualization of the same bear's huge impact upon lives of people affected with leprosy in terms of their various life process and expansion of life potentialities.

7.4.1 CULTURAL BELIEFS, PERCEPTIONS AND LEPROSY

This section is linked with above section of experiences of stigma and conceptualization of dignity by people affected with leprosy. When one looks at causes of stigma, it needs to be taken into account cultural beliefs and perceptions about leprosy and people affected with leprosy as held in larger societal imagination.

Leprosy is a highly stigmatized disease and much of social stigma is attributed to the prevalent myths like its hereditary and contagious nature, divine curses along with physical deformities caused. People who are affected not only suffer because of deformity but also because of intense psychosocial reactions from the community at large (Kaur.H and Brakel.Van W 2002a). Social ostracism and various kinds of myths towards leprosy and people affected is a no new phenomenon. Even during colonial times there were conceptions of hereditary and contagion mediated transmission of the disease, people affected with leprosy being sinners and suffering on account of their past life. It was seen as danger to elite imperial regime (Buckingham.J 2002). In Hindu *dharmasastra* based on mild and severe forms of leprosy distinctions were made in inheritance of property. These distinctions were based on leprosy sufferer's spiritual condition rather than just alone on medical health. A notion of morality and spiritual entity was associated with people affected with leprosy (Buckingham.J 2007).

Robinson's (1990)[82] conceptualization of leprosy in the form of three distinct but yet inter-related aspects is very important here to understand causes and forms of societal level attitudes towards people affected and impact of the same upon their lives. According to him, leprosy exists as a disease in biomedical terms, as an illness at the level of sufferer, and as sickness at the level of society societal perception. Experience of illness at a personal level is influenced to a great deal by socio-cultural factors and distinct societal perception can be associated with social stigma of leprosy. There are

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[82] Full article is inaccessible

various cultural beliefs associated with disease causation which have been documented by Wong ML and Subramaniam P (2002;3): *Punishments for sins , Immoral conduct e.g. sex with prostitutes, Bad blood/ unclean blood, Evil spirits/ Curse/Local charms/ Witch craft/ Breaking a taboo, God's will, Hereditary, Natural forces e.g. body humours, hot air, sea breeze, Food e.g. Hot/ cold, forbidden food, Under nourishment, Marrying/ having sex with a leprosy patient, Spontaneous appearance* etc. Awofeso.N (2011) reported about the perceived inter-linkages between leprosy causation and necrophilia/incest in Chinese and African settings.

Thus, based on this existing understand present study has tried to explore the same in the field setting based on life experiences of people affected with leprosy. Undoubtedly a lot of these perceptions/conceptions/notions still hold true on ground in spite of medical advancements and extensive health communication in relation with leprosy causation and symptoms.

It was observed that in the colony a belief exists based on perceived co-relation between affliction with the disease and one's *karma/* doings. Mythological notion associated with disease causation and its impact was quite common to see among research participants. Even outside the colony, residents from RK Puram slum also associated sins of past life as cause of their disease in the present life. This brings to fore an important aspect of relation between disease and religion. And this co-relation has existed historically since ancient times. Participants who were Christians or believed in Biblical teachings shared about Biblical philosophy about leprosy and Christ's love and healing of the people who are affected with the disease. Muslim residents of the colony also mentioned about attitude of Islam in relation with leprosy.

Participants brought in a dimension of mythological notion to their disease causation and suffering. They also shared about beliefs in general about leprosy which is widely held among people in spite of scientific advancements. A correlation was also brought to fore between food eating habit (beef) by a particular caste group and affliction with leprosy.

In relation with disease transmission and spread there are widely held myths in larger societal imagination. Participants shared about difficulties in marrying their children outside the colony. There have been instances where people just refused based on the belief that leprosy is hereditary. People from outside the colony also believe that leprosy is transmittable through air so some of them while passing through the colony pathway (which is used as a shortcut) actually cover their nose. This belief was confirmed more strongly from the way passersby actually stared at me with immense surprise while I sat in the colony next to people affected with leprosy.

Among the male participants it is also believed that leprosy brings early death to them. This is because of the fact that in their surrounding they have seen most of the men affected with leprosy dying at quite an early age. But upon inquiring I found out it was because of some other infection or co-morbidities like Tuberculosis or high blood pressure or Asthma or Diabetes.

Thus, in spite of wide thrust on leprosy related health communication people's beliefs and perceptions have been largely unaltered. Findings from the present study reflect the same. It is not easy either to all of a sudden ameliorate notions which have been held and passed across generations since ancient times. Simple awareness about the disease causation and transmission does not alter attitudes towards people affected with leprosy. It is important to realise that knowledge and information is very different from attitudinal responses of the society and perceptions about those affected. At a personal level, even if participants were well aware about the disease and its causation nobody is willing to pay attention to the same.

7.5 ELDERLY AND LEPROSY

In the literature nothing substantial could be located in relation with this theme. There have been passing references about age of people affected with leprosy but no further scrutiny beyond it. In the present study at least six research participants are in older age group (above 50 and maximum being 71 years). With repeated interactions in the field and reverting back to literature, it did unfold as one of crucial theme which has been under explored in the literature. Through this study effort is to bring issue of elderly and leprosy in the limelight. Indeed a lot more need to be explored but a glimpse of it is provided here based on the insights from their life experiences obtained in a limited span of time.

Present study can be seen at a micro level as contribution to the field because it enables to explore and understand various social life processes of elderly which have played and still continue to play an important role in their lives. Impact on health is one of the many outcomes. Stigma and indignity has been crucial in mediating varied experiences of elderly who are affected. This kind of understanding is important for a more informed, concerted and sensitive intervention in order to improve quality of life among elderly especially those affected with stigmatizing health conditions like leprosy who are often left out from mainstream discussions. For an envisaged empowerment of elderly with a surety of better quality of life, it is necessary to take into account these everyday lived experiences of elderly and incorporate this understanding at programmatic and policy level decision making.

There are various factors which are playing a crucial role in impacting their current health status. Apart from lifelong manifestations associated with leprosy ageing also impacts their life processes and health status immensely. Upon looking at health of elderly affected with leprosy and an elderly not affected with leprosy, this gradient emerges very clearly. A general close observation in surrounding settings and reflection about the same will reveal this. In this phase of life when one weakens physiologically and emotionally needs maximum support, elderly affected with leprosy are in a very critical state. Dependency is increased even more even to accomplish simplest life tasks and vulnerability is multi-fold in the case of elderly men and women who are staying alone. Life is disrupted for them in every dimension i.e. physiologically, emotionally, socially and economically.

Withered away social support networks and relationships coupled with inter-sectionalities between caste, class, gender crucially shapes their social experience of leprosy at a juncture when body is biologically aged and physiologically incapacitated because of the disease. All these existing conditions distinctly shape their treatment seeking behaviour and adversely impacts access to and utilization of health services. Older women are worst hit in the realm of existing gender inequalities. With no means of earning, any available social support network and absence of social security options, most of these elderly continue to beg in order to meet their daily essential needs. Presence of a partner is only form of support which exists for them. At a crucial stage of life when maximum support is needed, elderly affected with leprosy are left at the fate of destiny with a living identity of 'an old, leprous, disabled beggar'.

7.6 ROLE OF THE STATE IN THE LIVES OF PEOPLE AFFECTED WITH LEPROSY

Present section documents findings from the field which are based on various observations made over a span of time. Past and present life situations of people affected with leprosy are not entirely because of affliction with the disease. Institutions of the society like state have also a very important role in shaping of their lives in a very distinct and deprived manner (Staples.J 2007c). People affected with leprosy are a section of population even among marginalized who come last in hierarchy. They are out of any kind of social security net of the state. Health being a state matter also affects situation of people affected with leprosy. Although National leprosy eradication programme (NLEP) is a national health programme but its implementation is state specific with defined targets. There are stark variations in pension given to the people affected from state to state and some do not give at all. For example in Delhi it is highest (Rs 1800 per month). In the realm of chronic nature of the problem, piecemeal welfare measures of the state are highly inadequate to ensure a life with dignity to this section of population. Moreover, there are coercive laws in place which make affliction with leprosy even more dreadful. There are sixteen such laws. People from the field shared about various instances where they have actually fallen victim to these coercive laws.

There is a clear provision of three percent reservation for people with disability under 'The persons with disabilities (equal opportunities, protection of rights and full participation) act, 1995[83]'. In this act, 'leprosy cured[84]' is stated as one of the specified disabilities. Out of three percent, one percent reservation is ensured for people with locomotor disability (including leprosy) and cerebral palsy. People in the field did share about difficulties in securing even that 1% reservation in government jobs which are offered mostly at a lower rank. Although WHO has clearly defined grade 1 and grade 2 disability but yet there is no uniform understanding among health professionals about

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[83] Draft of persons with disabilities Bill 2012 proposes 5% reservation for disabled with 1% reserved for people with locomotor disability including cerebral palsy, leprosy cured and muscular dystrophy

[84] "Leprosy cured person" in the act is defined as any person who has been cured of leprosy but is suffering from---

(i) loss of sensation in hands or feet as well as loss of sensation and paresis in the eye and eye-lid but with no manifest deformity;

(ii) manifest deformity and paresis but having sufficient mobility in their hands and feet to enable them to engage in normal economic activity;

(iii) extreme physical deformity as well as advanced age which prevents him from undertaking any gainful occupation, the same. Participants did share about inability to get disability certificates in spite of disability because there is no clarity about the same. This is already one major problem reported by disabled people and in the case of leprosy it gets even more complicated. People in the field with grade 1 disability shared about instances of their request being rejected for health certificate at the level of health institution itself.

7.7 CONCLUSION

Major findings of this chapter can be put under the following points:

- Methodologically, present empirical work relies on life-history approach with a narrative enquiry which is the differentness rendered to this work.
- Life history accounts of all the research participants have enabled not only to see their life situations as a whole which is beyond leprosy but also acted as a means of venting out/expressing one's innermost feelings and emotions.
- All the colony residents including research participants earn a living by begging in order to meet their daily essential needs. This is one of their survival strategies in the realm of physiological incapacities, social stigma attached with their life and unavailability of dignified means of earning.
- Leprosy affects men and women in very different ways. This differential impact is crucial in the shaping of a distinct social and physiological experience of the disease among affected individuals.
- A holistic outlook of viewing broader life experiences of people with social determinants of health framework enables to better understand specific life experiences in relation with leprosy. These determinants are more structural in nature and continue to confront lives of people affected on daily basis.
- Social networks and social support created within them have a crucial bearing upon overall life experiences and specifically health experiences of people affected with leprosy.
- Identity of a *leper/bimar/kodhi/lachar* has gained a prime importance in the lives of people affected with leprosy. In fact their very recognition at large is through these socially constructed and mediated stigmatized identities. Buut there are multiple intersecting identities in the lives of people affected with leprpsy which need to be factored in.

- Collective sharing of stigmatized identity: Same identity of 'a leper' which became one of the biggest reasons for their expulsion from their native (forced or voluntary) has been a binding force for all of them here in leprosy colony of Delhi (for that matter even other colonies too).
- All the research participants and other residents of leprosy colony are migrants from various districts of North Karnataka. Study has enabled to understand close linkages between migration, urbanization and leprosy.
- Delay in seeking right treatment because of various reasons has drastically impacted the progression of untreated disease and subsequent manifestation in the form of disability.
- Medical pluralism has emerged as one of the themes wherein people affected with leprosy prefer to visit a range of indigenous health practitioners on account of several reasons. This only contributes in further delay to initiate the right treatment.
- A distinct '*pattern of resort with a hierarchy*' has emerged in treatment seeking behaviour of all the research participants. This is impacted by larger health culture of the community.
- To understand lives of people affected with leprosy in totality it is very important to pay attention to interface between biomedicine and leprosy and implications of the same in the lives of people affected with leprosy. Care after cure component is very crucial in stopping dehabilitation post treatment and preventing further damage.
- Bodily dissociation and self mortification is experiences by people affected with leprosy on account of deformed and marked bodies coupled with intense societal stigma.
- To subside intense episodes of pain substance abuse has been found to be very common.
- 'Leprosy illness' has become a greatest metaphor in their lives accompanied with multiple forms of identities with an undignified and stigmatized self.
- There are distinct causes, forms and manifestations of stigma in the lives of people affected with leprosy which need to be viewed within a context.
- Caste, gender, religion bear an important impact upon lives of people affected with leprosy.

- Stigma not only affects individuals affected with leprosy but also their family members which in turn restricts their life potentialities too.
- Impact of stigma is also very crucial which is reflected from a distinct shaping of life experiences of research participants. These are the people who have continued to face years of dehumanization, discrimination, humiliation and social exclusion. This has completely deprived them from their 'inherent human dignity'.
- A sense of dignified self is completely disrupted but yet deep down their hearts there is an unseen unspoken plea for self respect and a right to live with dignity.
- Donation and charity activities do help in meeting their material needs to an extent but their emotional needs are never ever met. Deprivation is not only material but also psychological.
- Dignity is dominantly seen as a moral quality which implies it is acquired by people affected with leprosy rather than being inherent simply by virtue of being a human being.
- Participants conceptualized key components of dignity as work, food, health, education for children, living conditions etc.
- It was observed that in the colony a belief exists based on perceived co-relation between affliction with the disease and one's *karma/* doings.
- Apart from lifelong manifestations associated with leprosy ageing also impacts lives and health status of elderly affected with leprosy.
- Health is a state matter and accordingly one gets see to variations from state to state based on programmes and policies in relation with leprosy. Coercive legislation of the state also feeds into stigmatization process.

Briefly, on the basis of above findings one can conclude that holistic approach in understanding life experiences and various processes shaping the same is essential. As a public health practitioner contextual understanding of stigmtaization process at the levels of cause, form and impact is very crucial along with conceptualization of dignity by people affected. Entire focus on leprosy alone without due cognizance of factors and various situations playing role in the lives of people affected with leprosy is highly inadequate.

CHAPTER 8: CONCLUSION

Broad objective of the present empirical work has been to understand lived experiences of people affected with leprosy residing in one leprosy colony of Delhi with a rendering of theoretical understanding based on the concepts of stigma and dignity. Study had begun with an initial assumption that in society at large, leprosy creates a dominant identity of '*a leper*' in the lives of those affected with the disease. Leprosy not only physically marks their bodies but also becomes a metaphor of pain and illness for entire life. This not only leads to fear in the minds of people in the society but also exhibition of stigma in various forms towards those affected with the disease. There are multiple trajectories through which stigma manifests in the lives of people affected. Amidst life situations of this kind their conceptualization about human dignity is also impacted hugely. But, over time based on field work insights it was realised that leprosy is in fact one of the many intersecting identities in the lives of people affected. These identities are also shared at a community level which constitutes as one of the major binding force for them. It is necessary to realise that, leprosy does act as a trigger but there are certain pre-existing contexts and situations which give rise to distinct kind of situations in the lives of people affected with leprosy across different spheres. This experience is of continuing kind and does cut across caste, class, religion and gender.

For the purpose of the study purposively eight research participants were sampled from a leprosy colony in South West district of Delhi. All of them are from poor to very poor backgrounds. A conscious mix of participants with a gender balance (4 males and 4 females) across caste, religion, status of leprosy related disability, spouse status has been chosen. In terms of age groups, a large proportion of them (six) are in an age group of 50 or above. This is a general situation in the colony where a large proportion of people affected with leprosy are aged.

Life history approach with a narrative inquiry was used to understand life experiences of the research participants. Free flow interviews with research participants, non participant observation and group discussions were conducted in order to collect primary data. Follow up interviews were conducted with the research participants in order to fill in the gaps and enquire more in detail.

Study has derived from a range of theoretical work in relation with the concepts of stigma and dignity. A theoretical understanding developed from the same has been analytically blended with field realities and participant sharings. To fulfil research objectives various aspects related with lives of people affected with leprosy like migration, gender, begging, social networks, health experiences, source of treatment, health related behaviours, interface with biomedicine, experiences of stigma, conceptualization of dignity etc have been studied in great detail. Present chapter attempts to summarize major findings from this empirical study. Areas for future research have been also highlighted.

8.1 MAJOR FINDINGS FROM PRESENT EMPIRICAL WORK: AN OVERVIEW

The major findings of the study can be summarized under four broad headings: life experiences of people affected with leprosy, health experiences, experiences of stigma and conceptualization of dignity & elderly and leprosy.

8.1.1 LIFE EXPERIENCES OF PEOPLE AFFECTED WITH LEPROSY

The findings of the study show that overall life experience of people affected with leprosy comprises of various life events and phenomenon's which all act in unison to give a distinct shape to their life trajectories. This experience has been looked within the spheres of begging by people affected, interface between gender and leprosy, role of social determinants of health in their lives, their social networks and migration to Delhi.

It was found out that begging is one of the key survival strategies for people affected with leprosy in order to meet their essential needs. This has been a major compromise made in life in absence of other dignified means of earning, societal stigma and one's own physiological incapacities. They neither like to do begging nor ever thought in life to end up in this way. Begging was an outcome of dehabiliation in the lives of all eight research participants who were siphoned off to beggary in spite of medically rendered non-infectious. Begging also contributes to multiple intersecting identities in the lives of those affected with leprosy.

Upon examining inter-linkages between gender and leprosy it was found out that men and women both are affected with leprosy in very distinct ways. Suffering is for both the sexes and vulnerabilities are created. But nature of the same is very different for men and women. Vulnerability to acquire infection, addressal of the same access to and utilization of health services, delays in seeing care, burden of ill health are all different domains of gender which play role in differential impact of the disease upon two sexes. Existing societal norms, iniquitous gender relations, cultural aspects, gender roles and responsibilities and power dynamics play a major role in impacting a distinct social and physiological experience of the disease. An attempt has been to use a gender lens to understand and analyse life experiences of both men and women affected with leprosy rather than trying to compare the two.

It is very much essential to view leprosy infection and related manifestations ingrained in social conditions of living and socially ingrained determinants of health. This aspect is historically well known but practical level incorporation of the same in largely missing. Social experience of leprosy is largely influenced by caste, religion, gender, poverty, social hierarchies and graded inequalities within the society, housing, education, work etc. Present study has brought to fore this inter-sectionality very clearly where participants are from poor to very poor backgrounds from lower caste groups. All of them are either illiterate or very lowly educated (upto 4th standard) except for one participant. Recognising social determinants of health and understanding how of the same in shaping of leprosy experience is very much crucial.

Role of social network and social support created within these networks was also investigated. Social support was found to exist both in positive and negative ways in the lives of people affected with leprosy which in turn impacts their health outcomes significantly. Stay in leprosy hospitals has been significant for all seven research participants who stayed over there. This was a place where informal toes were created based on commonly shared identities and positive social support was extended. In Delhi, their social network chiefly comprises of the colony residents or people affected with leprosy from other leprosy colonies especially those who are from the same state. By the larger society, leprosy colonies are viewed as stigmatized neighbourhoods but these same colonies are a place of creation and nurturance of social support for it residents including those affected with leprosy. In this network, there are no boundaries of caste, class, religion. All live with and are recognized with a commonly shared identity of a leper both at an individual and commune level. Repercussions of the same exist in the lives of their healthy dependents too. There is not only a resistance by the society outside to accept people affected with leprosy but also unwillingness among those affected too. This has resulted in creation of a entirely distinct ghettoised world of their own in the form of leprosy colonies where they have their set of rules and regulations. Same identity of 'a leper' which became one of the biggest reasons for their expulsion from their native (forced or voluntary) has been a binding force for all of them here in leprosy colony of Delhi (for that matter even other colonies too). They stay in leprosy colony as one large group which is often homogenously represented to outside world.

Migration is another important phenomenon in the lives of people affected with leprosy which was mainly triggered with their affliction with leprosy. All the research participants are migrants from North Karnataka and have been in Delhi for almost two decades or more then that. There is also a gender related dimension associated with migration which needs to be recognized. Males have migrated either singly or with their known person to Delhi based on prior known contacts. Women have migrated after their marriage along with their husbands. There have been various reasons which have influenced people's choice to migrate like stigma attached with their condition, marriage, in search of livelihood, absence of basic essential services in the native place. Migration also creates an identity of a migrant in the lives of people affected with leprosy which is seldom recognized. But this is reflected through no voter card, below poverty line BPL card, ration card etc in spite of being in Delhi for many years.

8.1.2 HEALTH EXPERIENCES OF PEOPLE AFFECTED WITH LEPROSY

This is another major domain which encompasses research findings related with overall health experiences of people affected with leprosy. It encompasses experiences of people affected with leprosy with health institutions, medical pluralism and hierarchy in pattern of resort, interface between biomedicine and leprosy, experiences of disease and illness. Effort has been to look at these various issues with a public health approach.

It was evident from narratives of all the research participants that a consistent time lag existed between first onset of signs/symptoms and resort to right treatment. In an absence of the treatment, disease continued to progress leading to deformities of limbs. Right at the first time when a patch was noticed, it was either ignored or denied or concealed in anticipation of societal stigma. In the case of women situation was even worse where either no attention was paid to her complaint or it was concealed else it would have hindered her marriage which is socially expected. One of the major reasons which contributed to delay was resort to indigenous systems of healing by people affected with leprpsy. A distinct patter of resort has been observed from one system of medicine to another and doctor shopping from one practitioner to another in a hope to get better, quick treatment. Attitude of the practitioner and relationship shared with people affected was also crucial in shaping the same. All the research participants preferred visiting to Bengali doctor in Delhi in spite of being familiar with biomedical practitioners both in government and private settings. Christian organizations have a major role to play in leprosy care and cure which has existed historically.

While looking at health experiences of people affected with leprosy it is also necessary to understand and critically analyse interface between biomedicine and leprosy. It was found out that in spite of leprosy non infectious status in medical terms people continued to experience various complications related with the disease. Stigma is still attached with the disease irrespective of medical certification about their status. Indeed biomedical cure by Multi Drug therapy (MDT) is required but sole focus on it is not sufficient. Care after cure component is necessary not only for their improved health outcomes but also to prevent dehabiliation.

Study highlighted a very crucial aspect of overall health experience of people affected with leprosy which was focussed on capturing their illness narratives. Narratives about their experiences of pathologized body and personal suffering are very crucial in understanding experience how the disease actually affects them physiologically, mentally and emotionally. These narratives also gave an opportunity to all the research participants as wounded story tellers to construct and connect their life stories with an expression about their pain and illness. Substance abuse both among men and women has been found to be rampant among them which is mainly in order to subside intense pain, suppress hunger and pacify their feelings of sadness. Leprosy is a disease of chronic nature and it is necessary to look at not only its consequence but also significance. A marked degree of bodily dissociation and self mortification on account of marked and deformed bodies was also observed among all the research participants.

8.1.3 EXPERIENCES OF STIGMA AND CONCEPTUALIZATION OF DIGNITY BY PEOPLE AFFECTED WITH LEPROSY

Present study could unpack the term 'stigma' at the level of causes, forms and impact as experienced by people affected with leprosy. Stigma is produced and perpetuated in a certain context which is socio-economic, cultural, medical, political and historical in nature. It is a dialectical process where 'otherness' is created by dominant other who act as stigmatisers. There is a culture of silence among those who are stigmatized and this stigmatization is deeply internalized by people affected with leprosy over the years. Stigma is experienced both at an individual and community level. Social ostracism of people affected with leprosy on account of stigma has in fact lead to creation of their own ghettoised world 'leprosy colony' labelled as 'stigmatized neighbourhoods' by the society at large. Natural history of the disease has much to do with stigmatising behaviour and attitudes of the people at large. Stigma is also manifested in health settings in various ways which is termed as iatrogenic stigma. This is crucial in shaping access to and utilization of services by people. Stigma is experienced by people affected with leprosy in various domains of their life, from their relatives, spouse, neighbourhoods, employer, health practitioner etc. Study also revealed that entire focus on just leprosy related stigma dilutes entire purpose of looking at stigma holistically as experienced by people affected. It is necessary to link the same with the context. As understood from participant sharing's, intensity of stigma has been less in cities including Delhi as compared to their native place in rural areas of Karnataka. But this in no way implies absence of stigma in cities.

It is very crucial to pay attention to impact of stigma which is reflected from a distinct shaping of life experiences of research participants. These are the people who continue to face years of dehumanization, discrimination, humiliation and social exclusion. This has completely deprived them from their 'inherent human dignity'. It wasn't like they never had human dignity or it was never acknowledged. But onset of the disease coupled with existing situations of life and its manifestation in various forms did disrupt it immensely. A sense of dignified self is completely disrupted but yet deep down their hearts there is an unseen unspoken plea for self respect and a right to live with dignity. In the lives of people affected with leprosy, 'accquired form of dignity' becomes a key to their right to live with dignity rather than inalienable inherent form of human dignity. It is viewed as a moral quality for them which is graded and depends on their status in life. It was also found out that research participants had a unique notion about their dignity. It did vary from person to person but essentially crux was same. There sharing's enabled in defining certain key components of dignity like work, food, health, education for children, living conditions etc.

8.1.4 ELDERLY AND LEPROSY

Present study gives a micro level picture of status of elderly affected with leprosy residing in a leprosy colony. Impact on health is one of the many outcomes. Apart from lifelong manifestations associated with leprosy ageing also impacts their life processes and health status immensely. Upon looking at health of elderly affected with leprosy and an elderly not affected with leprosy, this gradient emerges very clearly. Stigma and indignity has been crucial in mediating varied experiences of elderly who are affected. This kind of understanding is important for a more informed, concerted and sensitive intervention in order to improve quality of life among elderly especially those affected with stigmatizing health conditions like leprosy who are often left out from mainstream discussions

8.2 FUTURE RESEARCH AREAS

Present research study has been conducted within a limited time span but it highlights a range of issues which need further academic work to contribute to the field of leprosy. Based on the present work some areas which can be further investigated through research are mentioned below.

More intensive work needs to be done in relation with social determinants of health and leprosy. Studies with a more in depth scrutiny of inter-sectionalities of caste, class, gender, religion can be devised. Studies trying to explore and understand concept of human dignity in the lives of people affected with leprosy are very crucial as it is evident from the present work. Future work can be channelized in this direction too. There has been absolutely very little amount of literature looking at medical pluralism, hierarchy in pattern of resort and impact on health outcomes of people affected with leprosy. This can be also pursued by future researchers looking at social dimensions of leprosy. In relation with stigma, cultural epidemiological studies are very much relevant. This kind of work is really lacking at present. A very important area which needs academic attention is lives of elderly affected with leprosy. As encountered in the field, majority of people affected with leprosy were 50 or above. This is a group which is often left out both at the level of practice and research. This is something which needs attention by researchers to add to the body of literature in the field of leprosy.

ANNEXURES

ANNEXURE 1: DOCUMENTED CASE STUDIES OF EIGHT RESEARCH PARTICIPANTS

(1) Code: Go

Religion: Hindu **Caste**: Kurba Jati- Non lingayat **Age**: 55 **Sex:** Female

Education: Illiterate **Occupation:** Begging **Native:** Yadgir, Karnataka

Category: Old, severely deformed, husband and wife both leprosy affected

Leprosy status: Leprosy affected woman with disfigured limbs, clawed hands and feet

Marital Status: Married and stays with her husband Devappa who is also leprosy affected

Go aged 55, belongs to Yadgir district in Karnataka. She had come to Delhi around 20 years back after getting married. She has not attended any school education. Here in Delhi she stays with her husband Devappa who is also affected with leprosy. Her two children (one son and one daughter) stay in Karnataka. They are married and work in Bangalore. Her day typically begins at 5am and she goes to beg along with her husband in the first shift from 6am to 11am and then in the second shift from 2pm to 5pm. Sunday is a holiday for her since because of less rush, earning is also very minimum.

She was afflicted with leprosy 40 years back when she was 15 years old. She was married at an early age. She had patches at the time of her marriage. After an initial delay she resorted for treatment in Raichur District hospital. After being suggested by her sister she then shifted to a hospital in Hyderabad and her husband also accompanied her. Here her both the feet which were wounded were amputated up to her toes. After staying there for four months she returned back to her village in Yadgir. Later she shifted to RK Puram Leprosy colony in Delhi along with her husband.

In Delhi, she earns a living by begging on the streets along with her husband. Charity and donation activities which happen in the colony also provides her with materials of her necessity like blankets, clothes, sponsored cooked food and snacks sometimes, utensils, pulses and flour etc. She goes to beg in a hand cart which also saves her from being picked up by police under Anti begging act. She also gets a monthly pension of Rs 1800 from Government of Delhi[85].

In Delhi, she lives in the leprosy colony as a close knit family where all the residents are signified with a leprosy identity. Since all of them are from Karnataka, so culturally, linguistically and regionally they share commonalities. She also knows people residing in other leprosy colonies who are from Karnataka.

After coming to Delhi, her main source of seeking treatment is Bengali Doctor who practices in nearby RK Puram slum and ASHA Polyclinic which is run by Maitryee Mission. Although she is medically cured of leprosy and rendered non infectious after taking MDT Course during her treatment in Hyderabad but she lifelong morbidity on account of leprosy still persists. She suffers from neuritis pain and difficulty in eyesight. She receives weekly stock of two bandages and medicines which is delivered to the colony but very irregularly. She is fond of eating *paan* which according to her not only keeps her busy but also satisfies her appetite.

As of today life is the way it was when she came here with no much hopes for any change. Her life is synonymous with a daily scheduled routine of begging, doing household chores and then going to sleep with a repetition of same cycle every single

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[85] Initiated under Sheila Dikshit Government for people affected with Leprosy.

(2) Code De

Religion: Hindu **Caste:** Non Lingayat **Age:** 52 **Sex:** Female

Education: Illiterate **Occupation:** Begging **Native:** Gadag, Karnataka

Category: Old with disability, husband was leprosy affected, Widowed and stays alone

Leprosy status: Clawing of both hands and feet, ulcer on both feet

Marital Status: Widowed

De aged 52, belongs to Gadag district in North Karnataka. She is survived with one younger sister in her family who stays in Karnataka. She was married at quite an early age to a person who was also affected with leprosy. Later she shifted along with her husband to RK Puram leprosy colony in Delhi. After her husband passed away some years back, she stays here alone. She begins her day at 4am and goes to beg by 6am. She returns by 11am and goes out again in afternoon from 2pm to 5pm. After coming back she either eats food which is donated or cooks on her own, interact a little with other colony women and then goes to sleep by 9pm. She has not attended any school education.

She could not recall exact age at which signs and symptoms of Leprosy started to appear but she could faintly recall that it was some time during her teenage. She was orphaned at a very young age. She was taken to Bellary hospital for treatment by her sister. She did take medication for four years. At the time of admission to Bellary hospital, she was already married. She stayed there for two months along with her husband. She had resorted first to a private doctor for treatment but later she started going to Government Hospital. Treatment cost incurred because of visiting a private doctor was huge for her at that point in time. Presently she does not suffer from any complication or other disease. Her main source of availing healthcare facility is Bengali Doctor who has his clinic in adjacent Ambedkar Slum. Like most of other people in the colony she is also addicted. She chews tobacco and consumes country liquor. She does not feel hungry if she consumes the same.

Her main source of earning is from begging which she does twice every day except for Sunday and when she is ill. Going alone fetches her more earning which she would have to share otherwise with accompanying person. After coming back she counts all her money collected. Saves some and gives it her sister whenever she visits her in Karnataka. She also gets a monthly pension of Rs 1800 from Government of Delhi.

In Delhi, her social network comprises of people mainly from leprosy backgrounds of RK Puram colony or other colonies where people from Karnataka have settled down. Back home she keeps in touch with her sister and visits her during her yearly trip to Karnataka.

(3) Code Fa

Religion: Hindu **Age:** 65 **Sex:** Female

Education: Illiterate **Occupation:** Begging **Native:** Bellary

Category: Old, with disability, husband was also affected, stays with daughter, son in law and their kids

Leprosy status: Clawing of both hands and feet, Ulcer on right feet

Marital status: Widowed

'*Hum toh pehle ma-baap ghar hate. Par bimari aane se sab kuch chod chaad Bellary mein aa gaye aur wahan se Delhi*' (I used to be in my paternal home but because of the disease I shifted to Bellary and from there to Delhi)

Fa, aged 65, hails from a rural area (*kheda*) of Bellary district, Karnataka- not very far off from Bellary town. It's been more than three decades she is staying in this colony in Delhi. She is a widow and stays in Delhi along with her daughter, son-in-law and grandsons. She is eldest among four sisters. Her parents were involved in farming their own small patch of land along with farm labour rendered to bigger land owning castes in the village.

As she could recall, first time disease appeared on her body when she was seven years old. It was ignored for a long time thinking as if they are some skin rash or allergy. When she was 13 (around 1960), her disease worsened and it was diagnosed by Bellary government hospital as leprosy. Her medication was immediately started which was all free. Her medication (DDS-Laplone) continued for a total of two years and as a result her disease was considerably under control. Hospital was located close by in her *kheda* only. She did not visit any herbal doctor or quack etc for treatment.

She was actually left in the hospital by her parents once they came to know about it. There itself Fa met a man from Hubli who was also affected with leprosy. Later both of them got married and shifted to Bellary leprosy colony. They stayed in the colony for 10-15 years. There they adopted one girl child. As she started growing up, family needs also increased. She was compelled to start begging because meager earning by her husband (Rs 90 per month) was not sufficient to run household. Finally after struggling for few years, through some known contact she finally migrated to Delhi along with her daughter and husband.

After coming to Delhi, if there is any health complication she either goes to Bengali doctor or to ASHA Polyclinic or in certain case to private clinics which are located close by. For her back and knee pain she buys medicines over the counter which she used to get from Bengali doctor. She recognizes them by color. She does not prefer going to AIIMS or Safdarjung hospital which are located just close by. It's been just 6-7 years back only when her hands got more deformed (Claw hand). Presently she suffers from neuritis pain because of leprosy and acute back and knee pain which de-capacitates her completely.

In Delhi, her main source of earning has been through begging which she does twice every day except for Sunday. When her husband was alive she used to beg with him and now she begs with another lady in a cart. Her daughter and son-in-law do some small work in a private firm but their earnings are not sufficient to run household and bear the costs of living in a city like Delhi. She also gets a monthly pension of Rs 1000 from Karnataka Government, since she is enrolled in her native as a beneficiary.

Fa has continued visiting Bellary leprosy colony even today. Whenever she goes back to Karnataka on yearly basis, she does visit this colony. In Delhi, her social interaction is limited to her colony and other leprosy colonies in Delhi where people from

Karnataka stay. In her native, she does visit her sisters and keeps in touch with them on phone. As expressed by her, life in Delhi is certainly far more comfortable and less stigmatizing as compared to her life in Bellary and back in her village. She is happy being here although sometimes she does feel regret of leaving her native.

(4) Code Me

Religion: Christian **Age:** 50 years **Sex:** Female

Education: 4th Standard **Occupation:** Begging **Native:** Bangalore

Category: Deformed, stays alone, her daughter and son in law stay in the same colony

Leprosy status: Clawing of both hands and left feet, right hand anesthetic with left eye Lagophthalmous

Marital status: Widowed

Me, aged 50, hails from Bangalore, Karnataka. She has been staying in Delhi for past twenty years (1992). After migrating to Delhi she was married to a man (Hindu) from Tamil Nadu who was also affected with leprosy. He is no more. This was her second marriage. Presently she stays with her daughter, son-in-law and her grandson. In her family, she has one elder brother and one younger sister.

She was 10 year old when disease started to appear on her body. By the time she was 15, her disease progressed more. Very soon she had to drop out from her studies too because of her disease as well as financial situations. Her father had passed away at an early age and her mother had no idea about what to do. She was married when she was 18 and had a son by the time she was 20. This was the time when her disease progressed severely in an absence of any medical treatment. Her mother was advised by a doctor which **Me** called as Malaria doctor to visit hospital since she is suffering from Leprosy. She started her treatment in a private hospital in Bangalore. She took medication for two years. Deformity was already visible in her limbs.

Seeing her disease taking a severe shape, her husband who was a Christian left her. She had a love marriage with him. He then returned after ten years (she was 30 that time) and **Me** had a daughter after that. He deserted her again[86] and never came back after that. Her daughter was two years old that time. Then she shifted to CL Hospital hostel in Bangalore along with her daughter and her son stayed with her mother. She stayed there for three years. She received a vocational training in weaving sweaters. After three years she returned to her maternal home and continued weaving. She was paid for the same.

In the meantime she was asked to migrate to Delhi by her Uncle who was in CL Hospital in Bangalore. She migrated to Delhi alone with her five year old daughter. Her uncle knew her second husband who was also in CL Hospital for treatment and then went to Delhi to reside in a Leprosy colony. She came here and got married to him. She was 35 at that time. Her son was left in her native only with her mother for studies.

She survives in Delhi by begging twice every day. She never used to beg before coming to Delhi but under extreme situations of poverty coupled with no available means of earning she was compelled to begin begging. When her husband was alive she used to go for begging along with him. Since she did not like doing the same so she quit in between. Now, after he has passed away she had to start begging once again. She goes along with another woman from the colony in a cart and begs on streets. She does not receive any pension although she is eligible to get the same. Pension of her husband has also stopped after he passed away.

Presently, she suffers from lagophthalmous eye with severe pain, neuritis and extensive ulceration on account of leprosy. She goes to Bengali doctor or ASHA polyclinic in case of she feels unwell. In more complex situation she visits Nirmal or TLM hospital in Shahdara but these are very far for her.

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[86] He still stays in Bangalore and has remarried a healthy woman.

Her social network in Delhi comprised mainly of people from the colony and her sole support system is the family of her daughter. Her son is married and works in Bangalore as a painter. She occasionally keeps in touch with her sister and brother who are in Karnataka.

(5) Code MuS

Religion: Muslim **Age:** 58 **Sex:** Male

Education: Illiterate **Occupation:** Begging **Native:** Raichur, Karnataka

Category: Old, with disability, only he is leprosy affected and wife was healthy, Widower and stays with two small kids

Leprosy status: Clawing of both hands and feet with both eyes Lagophthalmous, ulcer on both feet

Marital Status: Widower

MuS aged 58, has been staying in RK Puram Leprosy Colony for past two decades. He is a native of Raichur in North Karnataka. His familial occupation was goldsmith's work. He has three brothers and there is one younger sister in his family who stay in Karnataka. Now he is a widower and stays with two kids- one small girl and one boy in his early teens. His son goes to school and takes care of household chores. His small daughter has dropped out of school and remains in the colony itself. MuS go out to beg everyday from 6am to 11am. Since he is very old and unable to walk and see properly so he stays back at home in afternoon.

He was 14years old when disease symptoms started to appear for the first time. Initially he was treated by a doctor whom he addressed as 'Malaria Doctor'. Later he was treated in CL Hospital in Bangalore. He took MDT treatment over here and stayed for two years. He stayed in the hospital all by himself without support available from any of his family members. Presently he suffers from various leprosy related manifestations like lagophthalmous eyes, neuritis pain and repeated ulceration on account of anesthesia.

He migrated to Delhi from Bangalore along with his friend (whom he met in CL Hospital) after halting at various places. He already knew some people in Delhi from his place. While migrating to Delhi he stayed in between in Bagalkot for a year and in Hubli for two years. After reaching Delhi, he got married to a lady who was much younger to him. She was staying alone in the same RK Puram colony. She recently passed away and now MuS is survived with two children. In Delhi, his sole and regular means of earning is from begging which he does every day in the morning. Since he is unable to see properly and cannot afford operation because of high costs involved, he goes in pair to beg which is shared after returning. They use a cart for begging which also protects them from being picked up by police. He is entitled to get a monthly pension of Rs 1800 which is very irregular.

MuS's social network in Delhi comprises of people from RK Puram leprosy colony and people of *Kannada* origin from other leprosy colonies. He does visit his brothers and sister when he goes to Karnataka in a year or two.

(6) Code Ya

Religion: Hindu **Caste:** SC (Harijan) **Age**: 71years

Sex: Male **Education:** Up to 4th Standard in Kannada Medium

Occupation: Begging **Native:** Bellary District, Karnataka

Category: Old with deformity and ulcers, only he is leprosy affected and rest all are healthy.

Leprosy status: Clawing of both the hands and feet. Ulcer on both feet

Marital status: Married and staying with wife and children

"*22 saal ka tha jab bimari lag gaya tha. Dard hota tha aur haath pair mein chatta aya tha. Log gaon mein atraaz karne lage toh sab chodkar yahan aa gaya*". (I was 22 when disease appeared for the first time. It used to pain a lot and there were patches on my hands and feet. People started objecting in the village so I left and came to this place)

Ya, aged 71, hails from Toranagallu village in Bellary district, Karnataka. He has two elder brothers and two sisters. In Delhi, he stays with his wife and he has two daughters and three sons. It's been more than three decades (since 1980) he is living in Delhi. He initially settled down in Tilak Nagar leprosy colony and then in 1989 shifted to RK Puram Leprosy colony. His children are now married and one daughter stays in Bellary leprosy colony.

Soon after his marriage, Ya started to get whitish spots (called *chatta* by locals) across his limbs. He was 22 year old that time. He used to do farming in his own field but due to complications on account of the disease progression he was compelled to quit. Very soon entire village came to know about his disease and people started objecting him and his family. People distanced themselves out of fear. Stigma and discrimination was so intense that he was left with no option except to leave the village.

He resorted to treatment much later when ulceration and resultant wounds had already severed. He was admitted in Bellary leprosy hospital and stayed there for three years. He underwent medication and regular dressing over there. Soon after completing his hospital stay he moved to Delhi along with his family to join 'people of his kind'. As of today in Delhi he does not go anywhere for treatment. If complications are too troublesome he goes to Bengali Doctor who is located closeby. He does self dressing at home and receives a weekly stock of the same although irregularly from Safdarjung. In the past, he used to visit Thangaraj Hospital (Now TLM Nandnagri Hospital, Shahdara) and Nirmal Hospital run by Missionaries of Charity Sisters near Kasturibagh, Tahirpur.

After coming to Delhi, he could not find any viable means of earning. He tried hard but all in vain. This eventually compelled him to begin begging in order to make his ends meet and fulfill essential daily needs of his family. He also receives his monthly pension.

In Delhi his only known social networks are people from the leprosy colonies mainly those who are from Karnataka. He goes annually to his native place during Moharram and if elections are there (his voter card is of Karnataka). He also visits his siblings and people in Bellary leprosy colony.

(7) Code Hu

Religion: Hindu **Caste:** SC (Harijan) **Age**: 40 years (28-12-1972)

Sex: Male **Education:** 10th Pass

Occupation: Works with MCD on contractual basis as sweeper

Native: Bellary District, Karnataka

Category: Middle age with deformity and ulcers, only he is leprosy affected and rest all are healthy.

Leprosy status: Clawing of both the hands and left feet. Ulcer on left feet

Marital status: Married and staying with wife Ratna and children

"*Hum toh bheekh mangta hai par phir bhi bheekh mangne mein kabhi kabhi sharam ata tha humko. Kab tak bheekh mangne ka? Hum bhi shaadi shuda hain, hamara bhi baccha toh hain*". (I beg but I do feel shame while begging. But for how long I will beg? Iam married, I have children!)

Hu aged 40, hails from Aerdoni village in Bellary district, Karnataka. He has been staying in Delhi for past 20 years. He is youngest of two brothers and has one younger sister who is married. In Delhi, he stays with his wife, children and son of his brother who is studying.

He observed first signs and symptoms of leprosy when he was 15 years old. He was in 10th standard that time but as the disease progressed he had to drop out of his studies. There were white patches on his body which were initially ignored and then attempts were made to treat herbally. This only lead to continued spread of the disease. Hu was married by the time he was 20 and had three kids from the wedlock. His disease intensified even more now. Finally he was taken to a Missionaries of Charity Hospital in Bellary as advised by one local Christian priest from his village. From there he was shifted for a year to government hospital in Bellary. This was only after 5-6 years of his marriage. He was treated for three years in total (two years Missionaries of Charity and last one year in Government hospital) and by the time he was 30 plus he was given leprosy negative certificate by the Doctor. Grade 1 deformity had already occurred by the time he was declared cured.

By the time he finished treatment his kids were quite grown up. Family needs and requirements had also increased slowly. Soon he migrated along with his family to Delhi in search of some work. He was told about Delhi by one of his known persons. He was told about availability of work opportunities in Delhi. Initially Hu landed in Jagat Mata Kusta Ashram, Tilak Nagar and then shifted to Jeevan Deep Kushta Ashram, RK Puram. Since then he is staying here.

Initially, he used to make a living by begging because in contrary to his hopes even in Delhi there was no viable means of earning available for him. He had never begged before in his life. But in Delhi at least there was a counsel of anonymity of begging and better living conditions. In 2003, he was recruited on contractual basis with Municipal Corporation of Delhi (MCD) as a sweeper paid on daily basis. Since then he is working with MCD and is not regularized yet. He also receives a monthly pension of Rs 1800.

Hu is well connected with his family in his native. Two sons of his brother are staying in Delhi and they regularly visit each other. He visits his native annually during vacation of his children. He stays in his parental home along with his family and relatives. In his workplace also people have positive and co-operative attitude and behaviour towards him. Hu's overall life story presents one of the positive stores from the field where life has been filled with struggles but as of present far better than many.

(8) Code Sh

Religion: Muslim **Age**: 40 years **Sex:** Male

Education: 3rd standard in Kannada medium **Occupation**: Begging

Native: Chudguppa Village, Bidar, Karnataka

Category: Middle age with ulcers, wife who is also affected with leprosy (clawing of both hands and both feet anaesthetic)

Leprosy status: Clawing of both the hands and right feet. Ulcer on right feet

Marital status: Married

"*Shuru mein pehle thode se haath mein aa gaya daag. Mote mote aake tut gaya woh. Bimari bahut ho gaya. Maa-Baap bhi koi nahin. Phir aage aage kar ke Delhi aa gaya*". (In the beginning there were patches on my hand. Disease was becoming worse. My parents were also not alive. Thus I moved to Delhi'.

Sh, aged 40, hails from Chudguppa village in Bidar district, North Karnataka. He has been staying in RK Puram Leprosy colony since 1990. He stays here along with his wife and eight year old son who studies in Bellary and stays in a missionary hostel. In his opinion, destiny played an evil game with him wherein first his parents passed away when he was very young and then the scourge of the '*bimari*' left him stigmatized and pained for the rest of his life. He was left with his elder brother who later got married and then Sh was left completely all alone.

Sh was 8 or 9 years old when first signs and symptoms of the disease started to appear on his body. Initially, he did not access medical treatment rather he was taken to some informal practioners by his brother. In an absence of right treatment disease progressed furthermore. It was much later after the disease onset that he actually resorted to Biomedicine and got admitted in Bellary Hospital. He was accompanied to the hospital by one of his known person. Before getting admitted into the hospital he also received DDS-Lamphine medicine from government doctors coming to his village. He was 14-15 years old that time and stayed there for three years. But still he was not very well.

His brother did not turn up even a single time for his care while he was taken to the hospital and his stay there.

After his treatment in Bellary hospital, he had nowhere to go except to migrate to Delhi. He was around twenty year old that time. He had heard about Delhi while being in Leprosy hospital. He came here all by himself and on his way took halt at various places. Those days there was no direct train to Delhi so he changed many trains and finally reached Delhi after a journey period of three months. On his way, he used to stay at station platforms or footpaths for 2-3 days and survive by begging. After reaching Delhi, he resorted to multiple agencies for to relieve himself from pain and suffering. He visited TLM Shahdara and Nirma Hospital. He also received medicines from Hind Kushta Nivaran Sangha. Even today he keeps getting ulcers and wounds as a result but he tries to take care of the same. He shared that after getting medicines from Hind Kushta Nivaran Sangh he was all right. He did not visit any other Doctor or government hospital for treatment. If something really troubles him too much he either goes to Bengali Doctor in adjacent slum or to ASHA polyclinic which is just close by. He receives his stock of two bandages and medicines from a van which comes from Safdarjung hospital. Bandages and ointments which are given often run short because wounds are more in number and require regular change. He also suffers from high blood pressure and diabetes. It's been ten years he is suffering from the same. He got this diagnosed in a government hospital in his native in Karnataka.

In Delhi, begging is the key source of livelihood for him. He did not used to beg from the beginning rather under certain circumstances he started begging. Unlike others, he does not go to beg every day. It's only when there is acute financial crisis comes he goes to beg and that too in residential areas. His wife does not beg rather she works as a housemaid in houses. She has not revealed about her place of residence because of the fear of societal stigma.

Sh shares a very minimal contact with his brother back home. He visits him just for formality when he goes back to Karnataka. He visits his native mainly to meet his son and be with him during vacations. He has actually nobody to call his own in his native. His small little world is in Delhi only comprising of people from the leprosy colony. For him, the biggest difference which disease made in his life was: he had to quit from his village and start begging to earn a living.

ANNEXURE 2: SOCIAL MAP OF THE COLONY

ANNEXURE 3: AETIOLOGY OF LEPROSY [87]

Aetiological agent in leprosy[88] is *Mycobacterium leprae*[89]. It is a slow growing bacteria which can take upto 20 years to incubate before having any observable effects (Covey.H 2001). It is not very contagious and only about 10% of people exposed to it actually get the disease and those that do have varied clinical manifestations (Carmichael, 1993; Nikiforuk, 1993 as cited in Covey.H 2001). It occurs in large numbers in the lesions of lepromatous leprosy, chiefly in masses within the lepra cells, often grouped together like bundles of cigars or arranged in a palisade. Leprosy[90] is known to occur at all ages from early infancy to very old age. Human being has been known to be only reservoir of infection in leprosy, except for the fact that naturally occurring disease with organisms indistinguishable from *M.leprae* has also been detected among wild armadillos in parts of southern USA. Among humans it is the lepromatous cases that carry the largest load of organisms.

Portals of entry and exit of *M.leprae*

The portal of entry of the bacterium into human body is not definitely known. However, the two portals of entry known as of now are skin and upper respiratory tract. The two portals of *M.leprae* exit often described are the skin and the nasal mucosa. However the relative importance of these two portals is not very clear yet.

The Prevalence pool

The prevalence pool of leprosy in a population in general is in a constant flux resulting from inflow and outflow. The inflow is contributed by the occurrence of new cases, relapse of cured cases and migration of cases. The outflow is mainly through cure or inactivation of cases, death of cases and emigration of cases. Of the various factors that

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[87] This section is a complete medical text which has been all taken from standard medical text for Tropical Diseases 'Manson's tropical diseases, 20th Edition'. " Noordeen SK and Pannikar VK **in** Cook.Gordon (Ed) 2002: Manson's tropical diseases- Chapter 58, 20th Edition, ELBS with WB Sunders print, UK ".

[88] If unchecked, it can lead to blindness, loss of neural sensation (anaesthetic limbs), and local paralysis with subsequent disability. Other co-morbidities such as secondary infections from syphilis, HIV, frostbite, diabetes, TB or injury often aggravates existing situations.

[89] *Mycobacterium leprae*, an organism closely related to the tuberculosis (TB) bacterium. Unlike TB, leprosy is difficult to contract and is rarely fatal

[90] Leprosy is also known as Hansen's Disease named after Gerhard Hansen, Norwegian Scientist who identified *M.leprae* and associated it with Leprosy transmission in 1873.

influence the prevalence pool, the importance of inactivation of disease[91] and mortality[92] are less well recognized.

Method of transmission of Leprosy

The exact mechanism of transmission[93] of leprosy is not known but possibility through respiratory route is most strongly held. The term 'contact' in leprosy is generally not clearly defined. All that is known as of now is individuals who are in close association or proximity with leprosy patients have a greater chance of acquiring the disease. In general, closeness of the contact[94] is related to the dose of infection, which in turn is related to the occurrence of disease.

Incubation period

In leprosy both the reference points for measuring the incubation period and the times of infection and onset of disease are difficult to define; the former because of the lack of adequate immunological tools and the latter because of the insidious nature of the onset of leprosy. The minimum incubation period reported is as short as few weeks and this is based on the very occasional occurrence of leprosy among young infants. The maximum incubation period reported is as long as 30 years[95], or over.

Sex Distribution

Although leprosy affects both the sexes, in most parts of the world males are affected more frequently the females, often in the ratio of 2:1. This preponderance of males is observed in as diverse geographic situations as India, Phillipines, Hawaii, Venezuela and Cameroon. It should be pointed out that male preponderance in leprosy is not universal and there are several areas particularly in Africa, where there is either equal occurrence of leprosy in the two sexes or occasionally even a higher prevalence among females. Such situations have been observed in Uganda, Nigeria, Malawi, Gambia, Burkina Faso, Zambia, Thailand and Japan.

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[91] Inactivation or cure due to specific treatment is an important mode of elimination of cases from the prevalence pool.

[92] Mortality in leprosy is often not considered important because the disease is rarely an immediate cause of death. However, leprosy patients are exposed to increased mortality risks due to its indirect effects.

[93] Contrary to popular belief, leprosy is is neither sexually transmitted nor it is inherited.

[94] Of the various situations that promote close contact, contact within household is the only one that is easily identified.

[95] Based on interactions with Leprologists at TLM and Netherland Leprosy Relief Foundation (NLR): Average time period is anytime between 5 years to 20 years.

Classification of Leprosy

Leprosy is mainly classified on the basis of clinical manifestations but it can also be classified by the pathological reaction of the tissues and the number of bacilli contained in them. The more definite forms of leprosy show a continuous spectrum of severity according to the immune status of the host, from the tuberculoid form, in which resistance is high, to the lepromatous form at the other pole, in which resistance is low. Between these extremes, there is a borderline (dimorphous) form which may show some characters of tuberculoid and some of lepromatous leprosy. Leprosy may also be classified according to the bacilliary presence[96] and this is extensively used in deciding treatment and in prognosis.

Multibacilliary (MB) leprosy contains all lepromatous (LL), Borderline lepromatous (BL) and borderline (BB) patients and also those borderline tuberculoid (BT) patients positive for *M.leprae* in the skin smears. Paucibacilliary (PB) leprosy contains indeterminate (I), tuberculoid (TT) and also those BT patients who are smear negative. The polar forms, TT and LL, are relatively stable but the BB form is unstable. Without treatment it tends to deteriorate to lepromatous. After treatment, sometimes it reverts.

Clinical features

The *natural history of leprosy* is very variable. The majority of people who come in contact with infectious lepromatous patients develop no symptoms or signs of infection. The majority of those who experience clinical effects mount a strong CMI response and develop tuberculoid leprosy. A minority who mount a weak CMI response or none at all develop lepromatous leprosy, a chronic progressive disseminated infection. A proportion of cases mount varying degrees of CMI response and develop borderline or indeterminate leprosy, and may then swing one way or the other on the pendulum, downgrading or upgrading depending upon changes in the immunological response.

Signs and symptoms

The mode of onset is variable. An early lesion may occur as a vague ill defined hypopigmented patch with some anaesthesia. The disease can also occur with multiple infiltrated patches or just diffuse skin infiltration. As compared with TB, one of the chief characteristics of leprosy is the absence of toxicity; enormous numbers of bacilli

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[96] After Ridley and Jopling classification given in 1966.

may be present in the body with few signs. The chronic onset is so gradual and insidious that the disease has advanced to a considerable extent before any abnormality is evident. There may be tenderness, tingling or thickening of a nerve, an area of anaesthesia, perhaps with some change in the appearance of the skin, insensitiveness to burning, formication, tingling or numbness of extremities. Discoloured skin patches may be mistaken for eczema or ringworm; these may first be small, gradually increasing in size.

Lepromatous leprosy, can be seen in persons with a negligible resistance; leprosy bacilli are widely disseminated throughout the skin, nerves and reticuloendothelial system. In addition, there may be bacilliary invasion of eyes, testes, bones and mucous membranes of mouth, nose, pharynx, larynx and trachea. Nerve involvement, in the absence of skin involvement, has not been described in lepromatous leprosy, but combined dermal and neural changes are usual. As sensory loss is often more pronounced than muscular wasting, patients continue to use the affected limbs and skin suffers much damage from repeated trauma owing to insensitivity to pain. Thus the hands become scarred from injuries and burns and trophic ulcers develop on the soles of feet. Secondary infection commonaly follows neglected trophic ulceration of feet or hands.Muscle wasting may produce deformities such as claw hand, main-en griffe, drop foot, facial palsy, but careful examination will show evidence of weakness long before paralysis occurs.

Other tissues such as nails of fingers and toes, mucous membranes, bones, reticuloendothelial system, testes, kidneys and eye can also be involved. Visual impairments and blindness[97] occur frequently in leprosy patients, particularly in those with advanced lepromatous leprosy.

Tuberculoid leprosy (non infectious) is seen in persons with a good resistance and may be purely neural or combined neural or dermal. The infection is never widespread but is localized to one area or to a few areas asymmetrically. Affected nerves are thickened, sometimes irregularly, and there are associated sensory or motor changes depending on the type of nerve involved. Sensory disturbances occurs as described under lepromatous leprosy, except for the fact that it occurs earlier in the course of disease. Motor changes are shown by muscle weakness or wasting and must be sought in the face, the intrinsic muscles of the hand and the dorsiflexors of the foot. Skin lesions take form of macules or infiltrations. These lesions are usually few, large and asymmetrically situated (face,

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[97] Leprosy is the third leading cause of blindness worldwide.

extensor surface of limbs, back and buttocks). Bone changes in hand or feet are less common as leprosy bacilli are not deposited in the bones or their nutrient arteries; also, the early development of muscle wasting and paralysis results in disuse and therefore reduced risk of repeated trauma. However, neuropathic atrophy may occur in the phalanges of fingers or in feet. Bone changes, secondary to disuse, to loss of sensation and to trophic ulceration may occur as in Lepromatous leprosy. Trophic ulcers of the feet are common.

Treatment

Treatment should be started as soon as a definite diagnosis has been made and the case classified as MB (LL, BL or BB) or PB (BT, TT or I). Multidrug therapy (MDT)[98] is now the standard treatment for leprosy.

Anti-leprosy drugs are no longer given alone and multidrug regimens are necessary to overcome Dapsone resistance, prevent resistance to other drugs. Two standard regimens are recommended (see the table 6).

Table 6 Standard treatment regimens for leprosy

	Multibacilliary Leprosy[99] (for Adults)	Paucibacilliary Leprosy (for Adults)
Rifampicin	600mg once a month	600mg supervised once a month for 6 doses
Dapsone	100mg daily self administered	100mg daily self administered for 6 months
Clofazimine	50mg daily self administered plus 300mg once a month supervised	

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[98] Modern drug therapy has led to establishment of country wide treatment programmes as part of Leprosy elimination. MDT comprises of Dapsone, Rifampicin and Clofazimine.

[99] Triple drug regimen for MB Leprosy must be given for a fixed period of two years. Relapsed smear positive patients should also be treated for two years.

ANNEXURE 4: CHECKLIST FOR FREE FLOW INTERVIEWS

Key points to be raised while interacting (flexible as per each participant):

a) How do they define (their idea) dignity, stigma, discrimination?

b) Illness experience:

- How do they look at their pain-suffering because of the disease?
- How do they look at their 'own diseased body'?

c) What do they think about self- How do they look at self- What is their idea of self esteem and respect (Atmasamman)?

- Ask especially in the context of Begging
- Construction of Dignity amidst a situation of constant discrimination and humiliation, stigma imposed by society and social exclusion coupled with material depriviation
- How do they feel when somebody donates (food, balnkets, clothes etc)
- Struggles and pain to feel treated as a full and complete human being
- Bodies being marked visibly for life: How do they look at their own bodies?
- Their aspirations in life: what do they want: will be more relevant for younger age group and what they always wanted: will be more relevant for older group
- Aspirations for Kids.

d) How people look at them?

- Within the family
- Neighbours
- In their *Gaon* (home town)
- Here in the colony in Delhi
- People in Delhi outside the colony

e) Nature and Range of violence experienced in life because of the disease or begging (like being picked up by Police) : 'Routinization of Violence and Indignity in their lives'?

f) What are their experiences with health service system vis a vis Doctors, Nurse, staff etc? (To explore possibility of iatrogenic stigma)

- To which all facilities did they resort to? (Pvt/Government/ Missionary/Self Cure/Quack or Bengali Dr/ Charitable Trust)
- Any health complications as of today: How do they deal/cope with it?

g) What are their experiences of being discriminated and humiliated or rebuked because of the *bimari or lachari*?
h) How do they look at the outside world in contrast to the world looking at them?
i) What makes them annoyed/ anguished/ irritated?
- Reactions like the one which I experienced when Thoverappa shouted at me
- Clicking Photos and Surveys?

j) Spouse relationship
- Their experience of being married in spite of leprosy (male and female)
- Their experience of living with a spouse who is healthy (male or female)
- Their experience of being affected with leprosy together (husband and wife both)

k) **Women:** Her experience of being affected with leprosy and her life journey (esp for people like Shankeramma)
- How male of the colony and the society look at them
- Do they think being a woman affected with leprosy makes them more vulnerable and miserable?

l) Migration and Disease links:
- How did they come to Delhi all the way from Karnataka (Might be related with stigma faced in Native place: Gaon)
- What kind of social networks they had in Delhi before coming and after coming here?
- Do they still visit their native place?
    - If Yes: What are their experiences?
    - If No: What are the reasons?

m) Caste-Class-Religion interface with Leprosy: Disease of poverty!!
n) Beneficiary of any kind of Government Scheme?
o) Sources of Livelihood.

ANNEXURE 5: LOCAL TERMINOLOGY USED

Kannada Word	English Word
Kami aagide Vamchane	Deprivation
Atyachara Himse	Violence
Bhedbhava Taaratamya	Discrimination
Horage iduvudu	Exclusion
Apmana/ Nachike gedu Avamaana	Humiliation
Maryade Gaurava	Dignity
Maryade illa Agaurava	Indignity
Kalamka	Stigma
Hesriduadu Patti hachchuvudu	Labelling
Kiri Kiri Aatanmka	Irritation, Anguish
Jati	Caste
Dharma	Religion
Saarvajanika aarogya vyavasthe	Health Service System (HSS)

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