SOCIAL DYNAMICS OF NON COMMUNICABLE DISEASES: A CASE STUDY OF DIABETES CARE AND MANAGEMENT IN THOUBAL DISTRICT MANIPUR

Thesis submitted to Jawaharlal Nehru University in partial fulfilment of the requirements for the award of the degree of

DOCTOR OF PHILOSOPHY

SAYA OKRAM

Centre of Social Medicine and Community Health
School of Social Sciences
Jawaharlal Nehru University
New Delhi-110067

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CENTRE OF SOCIAL MEDICINE & COMMUNITY HEALTH
SCHOOL OF SOCIAL SCIENCES
JAWAHARLAL NEHRU UNIVERSITY
NEW DELHI - 110067

Date: 18/07/2016

CERTIFICATE

This is to certify that this thesis entitled 'SOCIAL DYMANICS OF NON COMMUNICABLE DISEASES: A CASE STUDY OF DIABETES CARE AND MANAGEMENT IN THOUBAL DISTRICT MANIPUR' is submitted in partial fulfilment for the award of the degree of Doctor of Philosophy of Jawaharlal Nehru University. This thesis has not been previously submitted for the award of any other degree in the university or any other university and is my own work.

Saya Okram

Saya Okram

We recommend that this thesis be placed before the examiners for evaluation.

Dr. RAJIB DASGUPTA
(SUPERVISOR)

PROF RAJIB DASGUPTA
Centre of Social Medicine & Community Health
School of Social Sciences
Jawaharlal Nehru University
New Delhi-110067

DR. RAJIB DASGUPTA
CHAIRPERSON

CHAIRPERSON
Centre of Social Medicine & Community Health
School of Social Sciences
Jawaharlal Nehru University
New Delhi-110067

Telefax: +91-(11) 2670 4420 (Direct), 26742676, 26741557 (Ext. 4420), E-mail: csmchjnu@gmail.com
Web:http//www.jnu.ac.in/SSS/CSMCH/

ABSTRACT

Raising prevalence and incidence of Non Communicable diseases have been reported all over the globe with more burden and impacts on low and middle income countries. Several national reports and other regional based studies highlighted increasing NDCs risk factors and burden. These studies showed the reversal trend of NCDs which is affecting people in lower socio economic conditions and younger generation. In this thesis, care and management of diabetes is studied as a case study to explore NCDs within patients own social context. Linkage of social and material deprivation to disease incidence, access to care and treatment outcome has been shown in the conceptual framework of social determinants of health. This framework highlights the need to study social realities of an individual life for management of ill health. Focus on diabetes care has been predominantly come from the medical understanding which emphasises the physiological diseases and dysfunction while separating the illness experience of patients. Such focus could be a problematic situation in long term care of illness such as diabetes because it is an illness in which people live with it as part of their life due to its chronic nature. Emphasising on biomedical care might lead to over medicalisation thereby neglecting the importance of social realities of patient's life and their illness experiences.

This thesis aims to explore social dynamics and factors related with diabetes care at individual, community and health care professional levels in a district in Manipur. It attempts to answer the key questions: what are the factors influencing diabetes care and management among the study population? How do patients and care givers in different social context and background interact with available diabetes care services in the study area?

Data collection was carries out from February to October 2013 in Thoubal District, Manipur. The main study populations were type II diabetes patients, care givers and health care providers. Patients and care providers from the district hospital, a private clinic and members from a diabetes patients' network in the study community was included. This study employed qualitative research design. In-depth interview was conducted with 54 patients, 14 care givers and 18 health care providers and key health personnel of the district. A case study on community based patients' network called 'Diabetes self care society' was also carried out.

This study identified various factors influencing diabetes care and management at different levels such as individual/household, community/society, health care organisations, larger socio cultural and political context. Individual/household factors were socio economic status, their knowledge and perception on diabetes care, everyday living context and experiences with diabetes which give unique rational for their action in treatment seeking. Social norms of frequent events of feast in the community, diet and food culture unique to the community, belief and practices of super natural power/witch crafts were highlighted as socio cultural factors. Health care factors ranges from non availability, accessibility, affordability, acceptability and culture of traditional healing practices, availability of different forms of service provisions such as NGOs, patients networks, private as well as government clinics and traditional healers. Law & order and political situation of the study area such as frequent economic blockade, curfew and strikes, irregular payment of salaries even for government employees, lack of interest from the responsible authorities were also factors influencing diabetes care.

The findings suggested a comprehensive framework for diabetes care and management based on these factors. This framework indicated interplay and interaction of various factors in different levels. It gives significant information for development of policy framework which integrates conceptual understanding of social determinants of health approach to address issues ranges from individual level to social, cultural and political context. Given the strong cultural belief and social norm of traditional healing practices, a policy review should acknowledge the role of traditional healers by developing guidelines for integrating their services to bio medical system. Management guidelines and strategies should be specific to community context rather than implementing national or international standard guidelines. It also suggested the need of strengthening primary health care strategy for continuum of care and to cope with dynamic nature of diabetes care.

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LIST OF ABBREVIATIONS

ACCORD	The Action to Control Cardiovascular Risk in Diabetes
ADEPS	Amrita Diabetes and Endocrine Population Survey
AIDS	Acquired Immune Deficiency Syndrome
ANPLM	African Advocacy Network for People living with Non Communicable Diseases
ANM	Auxiliary Nurse and Midwife
AYUSH	Ayurveda Yoga Unani Sidha and Homeopathy
BMI	Body Mass Index
BMJ	British Medical Journal
BP	Blood Pressure
CHC	Community Health Centre
CHD	Chronic Heart Diseases
CHETNA	Children Health Education through Nutrition and Health Awareness
CME	Continuing Medical Education
CMO	Chief Medical Officers
COPD	Chronic Obstructive Pulmonary Diseases
CURES	Chennai Urban Rural Epidemiology Study
CUPS	Chennai Urban Population Study
CVD	Coronary Vascular Disease
DCCT	Diabetes Control and Complications Trial
DSCS	Diabetes Self Care Society
DALYS	Disability Adjusted Life Years
ECG	Electro Cardio Gram/graph
FCTC	Framework Convention on Tobacco Control
FGD	Focus Group Discussion
FPG	Fasting Plasma Glucose
FGT	Fasting Glucose Tolerance

GDP	Gross Domestic Product
HGP	Hepatic Glucose Production
HbA1C	Glycosylated Haemoglobin
HIV	Human Immune Deficiency Virus
IGT	Impaired Glucose Tolerance
IFG	Impaired Fasting Glucose
IDF	International Diabetes Federation
IIPS	Indian Institute of Population Study
ICMR	Indian Council of Medical Research
ICI	The Improve Control India Study
JNIMS	Jawaharlal Nehru Institute of Medical Sciences
LMICS	Low and Middle Income Countries
MOHFW	Ministry of Health and Family Welfare
MO	Medical Officer
MR	Medical Representative
NFHS	National Family and Health Survey
NPCDCS	National Program on Prevention and Control of Cancer Diabetes Cardiovascular Diseases and Stroke
NCDs	Non Communicable Diseases
NCRP	National Cancer Registry Program
NCMH	National Commission on Macroeconomics and Health
NUDS	National Urban Diabetes Survey
NGO	Non Governmental Organisations
NRHM	National Rural Health Mission
OHA	Oral Hypoglycaemic Agent
OPD	Out Patient Department
PHC	Primary Health Centre
PLWN	People Living with Non Communicable Diseases
PODIS	Prevalence of Diabetes in India Study

PRI	Panchayati Raj Institute
PVD	Peripheral Vascular Disease
RDS	Rural Development Society
RIMS	Regional Institute of Medical Sciences
RGI	Registar General of India
SDH	Social Determinants of Health
TNHSP	Tamil Nadu Health System Project
UN	United Nations
UKPDS	United Kingdom Prospective Diabetes Study
WDF	World Diabetes Foundation
WHO	World Health Organisation
2HPg	2 hour Post load Glucose test

CHAPTER 1

Introduction

As an epidemiological consequences to rapid socio-environmental change and population aging, profile of major causes of morbidity and mortality have altered. Mortality due to Non Communicable Diseases (NCDs) as a proportion to total mortality has risen. Rise of NCDs and their impact on low and middle income countries has gained increase attention in recent years. Various reports and academic publications projected an alarming trend by calling the spread of NCDs as a global crisis, in almost all countries. It is assumed that the NCDs usually afflict the rich people and are mostly concentrated among adults. The World Health Organization (WHO) global report (2005) on 'Preventing Chronic Diseases-A vital investment' tried to re-focus on the rising trend of NCDs in the world. The diseases once considered to be diseases of wealthy countries, the old and the rich are now showing a reverse trend with huge burden falling on low and middle income countries (LMICs) and poorer sections and young as well (WHO, 2005).

Four major NCDs that is diabetes, cancer, cardio vascular diseases (CVD), chronic respiratory diseases are given more focus in global as well as in academic circle when they talk about NCDs. Even though all these conditions have their own different natural history, treatment and management process, they have been clubbed together because of their common risk factors, (unhealthy diet, physical inactivity, use of alcohol and tobacco). Due to its chronicity nature, approach and strategy to manage these conditions in terms of response by health care system is similar. The focus of services provision should be towards long term care with consideration of patients and family member's perspectives on illness management as they live with the condition for life long.

In this thesis, among these NCDs, diabetes is chosen to carry out detail study on its care and management. It accounts for only 4% of total NCDs mortality however diabetes itself is a risk factor of other disease conditions leading to severe morbidities and premature mortality due to complications developed (ICMR, 2005). Raising prevalence of diabetes all over the globe has been reported in studies (Huizinga and Rothman, 2006). According to International Diabetes Federation (IDF), Diabetes

atlas, 7th edition, one in eleven adults has diabetes in which one in two with diabetes is undiagnosed. In 2015, 415 million people have diabetes; by 2040 this will have risen to 642 million. The number of people with type II diabetes is increasing in every country with 75% of people with diabetes live in LMICs. The greatest numbers of people with diabetes are between 20 to 64 years of age. In LMICs, the number of people with diabetes in urban areas is 186.2 million while 126.7 million live in rural areas. It is estimated that close to half (46.5%) of all people with diabetes around the world are not aware of their diseases (IDF, 2015).

Increasing prevalence among the younger age group, increasing out of pocket expenditure, rising rate of complications, rise in prevalence of risk factors and also Pre-diabetes, delayed diagnosis, limited health care facilities, sub optimal diabetes control are some of the challenges posed by type II diabetes in India (Ramachandran et al. 2013).

Interaction of several modifiable and non modifiable risk factors which includes unhealthy diet, physical inactivity, smoking, use of alcohol, family history, genetic, body mass index (BMI), greater waist circumference and waist to hip ratio along with changes in environment where we live such as urbanisation, globalisation are suggested as causes of diabetes (Mohan et al. 2007). In the context of raising prevalence in India, genetic predisposition is considered as high risk factor among Asian Indian.

Diabetes care and management is considered to be one of the most difficult tasks as it involves changes of the way patients and their family members live such as changes in diet. Late diagnosis of diabetes leading to fast advancement to various complications, lack of knowledge and awareness, patients' ignorance are often cited as barrier to successful diabetes care which is again complexes by inadequate health care infrastructures and professionals (Ramachandran et al. 2005; Albeti et al. 2007). Recent development in works on health inequalities put forward the framework of social determinants of heath in studying disease incidence and management. This emphasised that individual social characteristic age, gender, caste, class, education status, occupation, how a person live, his very day life along with his environment and society/community, larger political economic characteristic of the country he lives interact with one another to act as 'risk factors of the risk factors' and influence

their health seeking behaviour, treatment and health outcomes (Raphael et al, 2003; Stuckler and Siegel, 2011). Therefore, like other health conditions, diabetes management should be study and understand in this social context.

This chapter presents the aim and purpose of the thesis, motivation of the researcher to choose diabetes as area of interest for this doctoral thesis. It is followed by over all research design and organisation of the chapters and summary of each chapter. Last part of the chapter presents working definitions and terms used in the thesis.

Aim and purpose of the study

This study aims to examine social dynamics of diabetes in relation to care and management at individual, community and professional level in Manipur. Under this broad objective this thesis aims to study knowledge and perspectives, health seeking behaviour, challenges and barriers to successful diabetes management, outline the life stories and illness narratives of patients, impact in family and coping strategies. It also studied health care provider perspectives on diabetes care. The case study of diabetes patient network 'Diabetes self care society' aims to show an evidence on how social network of patients can be a platform for social support in diabetes care. A number of research questions are developed to achieve above mentioned purposes as follows:

1. What are the knowledge and perceptions of diabetes care and management among patients and care givers in the study area?
2. What is the health seeking behaviour and self care practices of patients and care givers in diabetes care?
3. What are barriers and challenges in diabetes care faced by patients and care givers?
4. How do their experiences of living with diabetes impact their management practices and self care activities and how do they cope with diabetes.
5. What are the perspectives of health care providers in diabetes care and available diabetes care services in the study area?
6. How can a patients network 'diabetes self care society' provides a platform for social support in diabetes care?

1.1 Motivation for this research

This research work is motivated by researcher's personnel experiences of being a care giver and living with diabetes patients in the family. This is also influenced by her academic and work experiences. During her study in Master in Public health, she had conducted short term study on Obesity, eating habits and diabetes among the school children as part of a credit program. This introduced the researcher to the ever growing problem of NCDs. However, the approach researcher had learnt from this short term project on how to find solutions for health problems was very much focus on technical issues related to medical advancement.

After joining the PhD in Centre of Social medicine and Community health, Jawaharlal Nehru University the researcher learnt about completely new concepts on understanding broader dimensions of health as social, political and economic concept and it has to be look beyond its bio medical gaze. This influenced the researcher's interest in social dimensions of health.

Another personnel experience of having a diabetes patient in the family made her realised the challenges of successful management of diabetes by the individual as well as at the household level, contradictory explanations of disease condition between the patients and doctors, changes in the life of patients as well as life of family member. This triggered the researcher more into knowing and looking for a way to better diabetes management. This interest was only at the individual and family level. During this time researcher had the opportunity to do volunteering work in International Red Cross and International Lions club in Thoubal district, Manipur. Various health camps, awareness campaigns on diabetes were conducted at community level. In such community camps she interacted with diabetes patients and become close with many of them that they often shared about their illness stories, worries, emotional and insecurity in life. She also got to observe the nature of charity and free services provided during these camps that most of activities were contracted to private diagnostic centres, pharmacies and private clinics. Given the situation of poor and inadequate government health care institutions, patients were more depending on private sector.

All these instances that happened as personnel, family experiences, academic and professional opportunities motivated the researcher to carry out a study on diabetes

care and management with focus on perspectives of patients and care givers, health care services available and providers within their social context.

1.2 Overview of study design

A qualitative research design is used to study diabetes care and management in Thoubal district, Manipur. Data was collected by conducting in-depth interview of patients, care givers and health care providers. Key informants interview was also done with key health officers. Focus group discussion was carried out with the members of the patients' network. These data collection started from February till October, 2013. A total of 54 patients who were from different socio economic background, different clinical profile was selected purposely from the district hospital, private clinic and patients' network representing patients from the community to provide a wide range of different characteristics of the respondents. 14 care givers and 18 health care providers including doctors, nurses, key health officials and traditional medicine practitioners/healers were also interviewed. Data was presented by identifying into themes, sub-themes and used descriptive and interpretative analysis approach.

1.3 Outline of the chapter organisation

Including this introduction chapter, this thesis has total seven chapters.

Chapter two is review of literature and conceptualisation of the study objectives. This chapter gives background information on current situation of Non Communicable diseases (NCDs) around the globe with focus on developing countries and particularly India. Next section of the chapter extensively deals with burden of diabetes, its epidemiology, care and management in India. Last part developed the conceptualisation of the study and formulation of research questions and objectives.

Chapter three presents research methodology. It includes rational for adopting qualitative research design, descriptions on study area, Thoubal and rational for choosing this district in Manipur. Detail study design explained about study respondents, how they were recruited and sample size and sampling strategies. Methods of data collections, analysis and interpretation are also described. Analytical framework for discussion of study findings which was developed from different research works on diabetes care and management is presented in the last part.

Chapter four, five and six are presentation of the study findings.

Chapter four presents major findings on diabetes care and management issues and information shared by patients and care givers. This includes themes and sub themes on knowledge and perspectives on diabetes care, health seeking behaviours, challenges and barriers, coping strategies and impact in life of family members.

Chapter five describes diabetes health care services available in the study district Thoubal and perspectives of health care providers on management and self care practices of diabetes patients, their suggestion for better management of diabetes. Findings on diabetes care practices of tradition healers are also presented.

Chapter six presents diabetes patients' network 'Diabetes self care society'. Findings on history of the formation of the network, its objectives, activities and views of members on its benefit as platform for social support is described in this chapter.

Chapter seven is the discussion and conclusion chapter. This chapter brings together the major findings of all the above three chapters and discusses in the analytical frame work described in chapter three and literature review on chapter two. Implications on policies level, primary health care and community mobilisation, recommendations and conclusion are presented.

1.4 Key terms and words used in the thesis

Diabetes: Originally this thesis intended to study both type I and II diabetes. During the pre pilot and pilot study, the researcher had the opportunity to interact type II patients as well as 4 parents of type I diabetes patients through the contact of doctors included in the study. However during the time of actual data collection, type I patients were not able to include in the study due to serious health conditions of the patients and 2 of them had shifted their house outside the state. Therefore, in this thesis all the respondents are type II diabetes patients. Patients with at least one years of diabetes were the inclusion criteria as the study aims to explore patient's lived experiences and health seeking behaviours. Therefore, including patients with more experiences would give larger and deep understanding of the study subject.

Diabetes care and management: For this study purpose diabetes care and management refers to activities and practices follow and carry out by patients and

care givers, health care providers including doctors, nurses, key health personnel, and traditional medicine practitioners/healers. It includes health seeking behaviours, perspectives and knowledge, challenges and barriers, their everyday coping strategies.

Knowledge and perspectives: Knowledge in the context of the study refers to the facts known by the patients or care givers and their experience about diabetes mellitus. Perceptions refer to their thinking and view of diabetes and its manifestations within their social context (Nguma, 2010).

Social dynamics: It is defined as interaction of technology oriented, aggressive treatment approach of available health care services and providers with patients within their own social context and perspective on diabetes care and management.

Traditional medicine practitioners/healer/herbalist: A Person who uses herbs/vegetables/plants/animals/mineral products based on local socio cultural and religious knowledge to cure illness and who is accepted by his/her own community as provider of local health care.

CHAPTER 2

Review of literature

This review of literature chapter is presented in following different sections. First section is about overall Non communicable diseases (NCDs). This is again further divided into different sub headings such as NCDs and risk factors, social determinants, burden of these conditions, impacts on socio economic, responses and strategies to tackle rising burden of NCDs. These reviews are first presented in global scenario than follow by specific studies on India. As described in details following section, NCDs covers a wide range of heterogeneous conditions, this research work choose to focus on a particular condition that is Diabetes. Thus, second section of the chapter presents literature on diabetes, its burden, issues with diabetes treatment, care and management, current policies and programs on diabetes prevention and control globally as well as in India. Third section of the chapter is about the conceptualisation of the problem of diabetes care and management in the context of present health service system of India and how diabetes care has been shaped. This is being used as conceptual frame work for the further development of this research work.

2.1 Non Communicable Diseases: What are Non Communicable diseases?

The term NCDs refers to a group of chronic conditions that are not typically caused by a virus or infection but exposure to multiple risks, slow in progress, log lag periods between exposure to risk and hazards to actual manifestation of signs of clinical illness resulting to chronic conditions which need for a long term treatment and care.[1] It is often discussed as synonymous to cardiovascular diseases (CVD), cancer, diabetes and chronic respiratory disease (COPD) which are four main NCDs. Digestive diseases, neuropsychiatric conditions, genitourinary diseases, endocrine disorders, musculoskeletal disease, skin disease, congenital anomalies, sense organ diseases and oral conditions, injuries are also included in NCD conditions. However,

[1] http://www.who.int/topics/noncommunicable_diseases/en/, Accessed on 2nd January, 2015.

emphasis has been given to four main diseases CVD, Cancer, Diabetes and COPD because of major risk factors they share (unhealthy diet, physical inactivity, tobacco and alcohol use) and due to their attribution to larger number of death (Stuckler and Basu,2012). It has been stated that by focusing on these common risk factors more lives could be saved.

2.1.1 Risk factors, causes and social determinants of NCDs

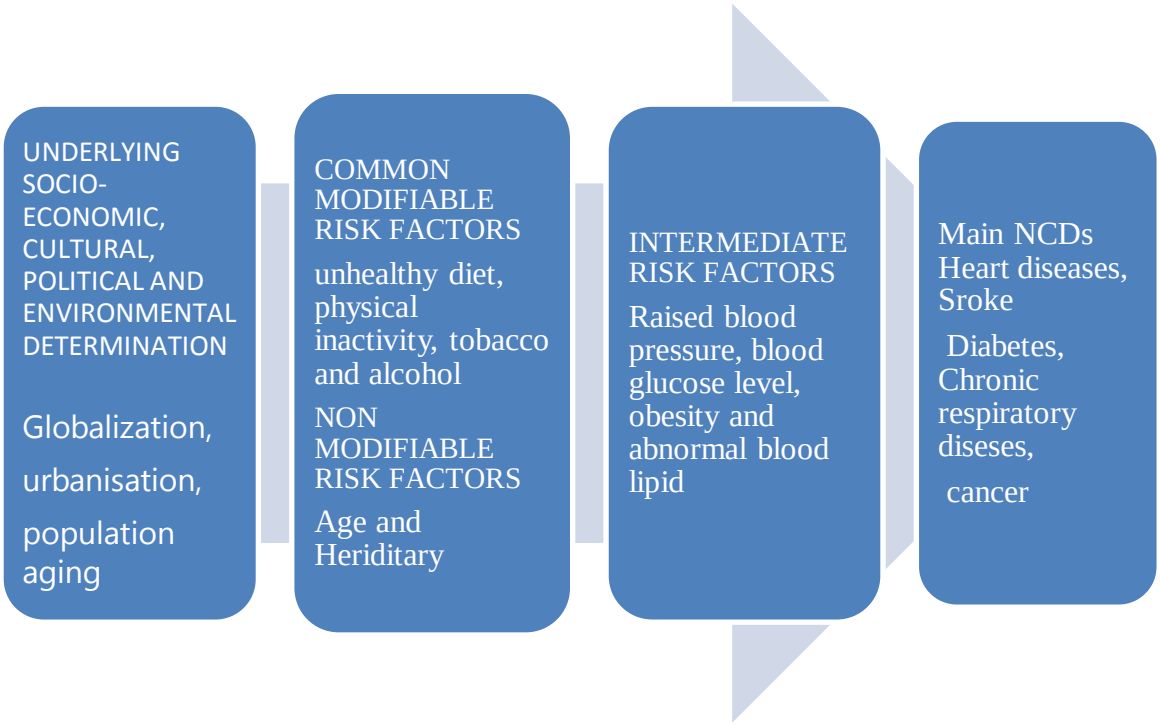
Four main behavioural risk factors have been identified as well known causes of major NCDs (CVD, cancer, diabetes and COPD). These risk factors are unhealthy diet, physical inactivity; tobacco use and alcohol use (also refer to as proximal factors). Various research works highlighted that these risk factors in interaction with non modifiable risk factors such as heredity, age explain the causes of CVD, cancer, diabetes and COPD and they work through another set of biological risk factors that are high blood pressure, raised glucose level, obesity and abnormal blood lipid (WHO, 2005). This explanation of causation implies that the way people live 'get under their skin' to cause chronic diseases. This simple biological/physiological explanation of the causes of NCDs might undermine the important underlying causes which is term as 'causes of the causes/ risk factors of the risk factors' of these conditions (Stucker and Basu, 2012). Following figure 2.1 shows the interactions of various factors in different levels that causes these diseases.

As defined by Krieger in her eco social theory, reality is far more complex, different causal factors are interrelated and this tangle webs contributed to individual chronic disease outcomes (Krieger, 1994). Therefore understanding the social determinants of health of these diseases is an important call in order to developed public health interventions and strategies.

In Social Determinants of Health (SDH) framework, above mentioned biological and behavioural risk factors are influenced by social position of the individual i.e. education, occupation, economic status, gender, housing ect. Inequality in health outcomes, risk factors prevalence, and access to care could be analysed from this perspectives. Studies have shown that these unhealthy behaviours like consumption of unhealthy diet, less intake of fruits and vegetable are common among the disadvantage section of the population with lower economic and educational status. As described within SDH framework, material circumstances of people that is their

community or neighbourhood environment such as proximity to process food outlets, tobacco, cigarettes selling places, inaccessibility to sidewalks, poor housing largely influence behavioural risk factors. Structural determinants of health like macro level socio economic factors, national, global politics, cultural factors, policies development strategies context of a country shaped the macro level root causes of NCDs. So, important question here is that are the choice of unhealthy behaviour by an individual is independent of his/her living circumstances. Many of these risk factors come from the social, cultural and environmental context of daily living and more broadly political, economy and social development policies of the country. This framework gives an insight that increasing prevalence/incidence of risk factors and NCDs among the poorer section of the society is a social process rather than a biological process (Raphael et al. 2003; Brown et al. 2004; Stuckler and Basu, 2012). This highlights the need of multisectoral approach in strategies and policies to prevent and control NCDs.

Figure 2.1: Interaction of causes of chronic Non communicable diseases



Source: Adapted from WHO (2005). Preventing Chronic diseases a vital investment, pp. 48.

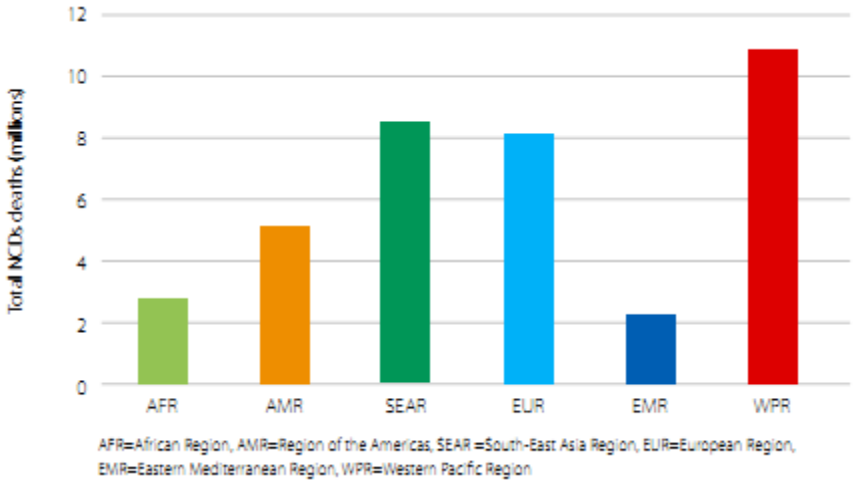
The following sections present an overview of global scenario with special focus on low and middle income countries (LMICs) and the emergence of NCDs in India.

2.1.2 NCDs burden

According to Global status report on NCDs published by World health organisation, 2014, NCDs accounted for 38 million deaths out of 56 million deaths occurred worldwide during 2012. Since the year 2000, number of deaths due to NCDs has been increasing in all the regions with most of these deaths are occurring in Low and Middle income countries. As shown in the following figure, increase in NCDs death is more in the WHO South-East Asia region, (6.7 million in 2000 to 8.5 million in 2012) and in the Western Pacific region (8.6 million to 10.9 million). It is projected that total annual number of deaths will increase to 52 million by 2030. Overall, age-specific NCD death rates are nearly two-times higher in LMICs than in high income countries. Approximately 42% of NCDs deaths are occurring before the age of 70 in 2012. It was 14.6 million in the year 2000 and it has increased to 16 million in 2012. Majority of these deaths are in LMICs with the higher proportion (48%) of deaths occurring in people under the age of 70 years, compared with high-income countries (28%). Fig 2.3 shows the proportion of NCD deaths by cause in 2012 among people under the age of 70 years. Cardiovascular diseases were responsible for the largest proportion of NCD deaths (37%), followed by cancers (27%), and chronic respiratory diseases (8%). Diabetes was responsible for 4% and other NCDs were responsible for approximately 24% of NCD deaths (WHO, 2014).

These data highlights that NCDs are major killer in all region of the world and increasing in faster rate in LMICs and they tend to die at younger age from NCDs than in rich and developed countries. The increasing burden of NCDs in low and middle income countries contributes to poverty. Its chronic nature leads to poor households falling in the cycle of debt and illness (Beaglehole et al. 2011). Beyond the direct health related implications, the cost of burden will also impact on the socio-economic status of individual, their household as well as country as whole.

Figure 2.2: Total NCDs death by WHO regions comparable estimates, 2012



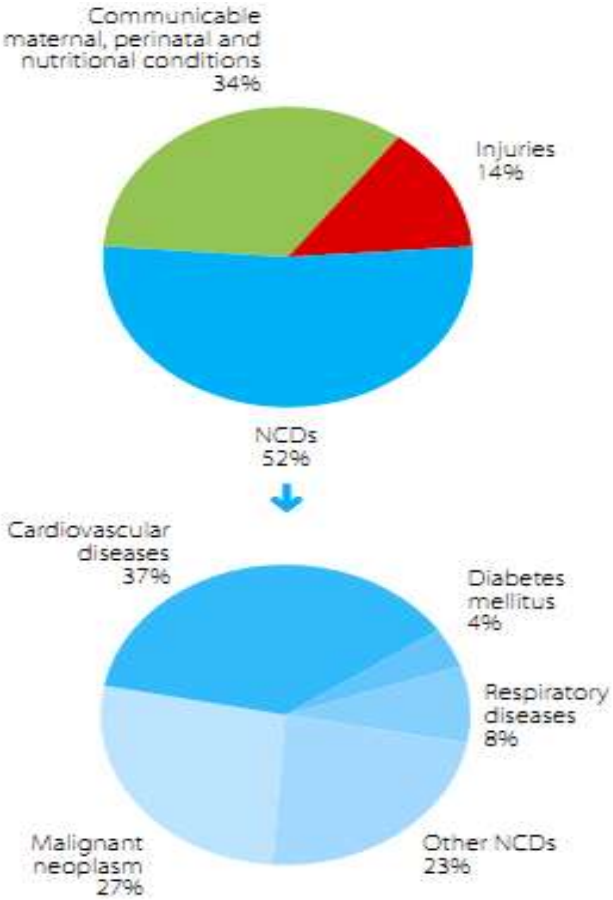
Source: World Health Organisation: Global status report on NCDs, 2014.

2.1.3 Social and economic consequences of NCDs

NCDs impact on economies, health system, individuals as well as their household directly or indirectly. It usually affects individual at productive age group and causes some degree of disability. Along with this, its cost of long term treatment and care affects individual and their households due to loss or decrease of earning, income, savings and assets. This put them at risk of poverty and cycle of dept and illness (World Bank, 2011). Delay in treatment seeking due to inability to afford care in time causes more complications thereby increasing cost of care and leading to more health and economic inequalities and reducing household savings (Mahal, karan and Engelgau, 2010). Evidences across the countries highlight the strong fact that cost of care for NCDs causes household poverty and catastrophic health expenditures. The share of out-of-pocket household health expenditures on NCDs in India increased from 31.6 percent to 47.3 percent between 1995–1996 and 2004. Moreover, 40-60 percent of these expenditures were financed by own saving and income and 30-35 percent by borrowing (Engelgau, Karan and Mahal, 2012). In Tanzania, cost of diabetes care is 25% of the mnimum wages which is beyond the affordable level of most of the population in this country. In South Asia, the chance of incurring catastrophic hospitalization expenditures was 160 percent higher for cancer patients and 30 percent higher for those with cardiovascular diseases than it was for those with

a communicable disease requiring hospitalization (Engelgau et al. 2011). Not only affecting health of sick member, other members of family have to compromise in variety of ways like selling valuable household assets, giving up on children education, reducing food expenditure thereby greatly reducing the quality of life and increasing social suffering.

Figure 2.3: Proportion of global deaths under the age 70 years, by cause of deaths, comparable estimates, 2012.



Source: World Health Organisation: Global status report on NCDs, 2014

From a neo-classical economics framework, this household cost of NCDs have considerable macroeconomic effect, reduction in labour supply and output, lower return in human capital investment, increased public health and social welfare investment. It has been predicted by world economic forum that in high and upper income countries, cumulative loss in global economic outcomes due to NCDs mainly heart diseases, stroke, alcohol misuse, cancer and depression would be $47 trillion or 5% of GDP by 2030 (David et al. 2011). It is further estimated that yearly economic growth would be reduced by 0.5% for every 10% in mortality due to NCDs. On this basis, World Economic Forum ranks NCDs as top global threats to economic development (Beaglehole et al. 2011).

This so-called epidemiological transition- the change from a burden of disease dominated by mortality from infectious causes to degenerative or chronic causes (Omran, 1971 as cited in Miranda et al. 2008) compounds the difficulties of addressing infectious diseases in ill functioning health systems creating double burden that causes poverty and slows development (Chand, 2012).

2.1.4 Global response to emerging NCDs in LMICS.

Rise of NCDs and their impact on low and middle income countries has gained increased attention in recent years and sometimes described as ‘race against the time’ (Leeder et al. 2004). Various reports and academic publications project an alarming trend by calling the spread of NCDs as a global crisis, in almost all countries. The World Health Organization (WHO) global report (2005) on ‘Preventing Chronic Diseases-A vital investment’ tried to re-focus on the rising trend of NCDs in the world. According to this report the diseases once considered to be diseases of wealthy countries, the old and the rich are now showing a reverse trend with huge burden falling on low and middle income countries (LMICs) and poorer sections and the young as well (WHO, 2005).

In the year 2000, World Health Assembly endorsed ‘Global strategy for the prevention and control of NCDs’ with the vision and framework of reversing the NCDs epidemic. It sets out 3 objectives: mapping epidemic of NCDs and their causes, reducing the main risk factors through health promotion and primary prevention approaches, strengthening health care for people already afflicted with NCDs (WHO, 2011).

The key landmark in policy development and strategic initiatives that have witness during more than 10 years after the endorsement of WHA strategy are:

1. WHO framework convention on tobacco control (FCTC), 2003
2. Global strategy on Diet, physical activities and health (World Health Assembly) 2004
3. 2008-2013 Action plan for global strategy for the prevention and control of NCD, 2008
4. Global strategy to reduced the harmful use of Alcohol, 2010

During this time, even though there were efforts from researchers and policy makers, issues of NCDs did not get much attention in the beginning. However, in the past 5- 6 years, the Lancet in collaboration with WHO published the series 'The neglected epidemic of chronic disease ' and 'Preventing Chronic Diseases-A vital investment' in the year 2005. This highlighted the huge burden of chronic diseases most of which is in LMICs such as India and China (Beaglehole et al. 2011). According to this report, Global response to NCDs is inadequate and despite global successes, such as the WHO Framework Convention on Tobacco Control, first legal instrument designed to reduce tobacco-related deaths and disease around the world, chronic diseases have generally been neglected in international health and development work. The report further mentioned that such negligence is due to several misunderstanding about chronic diseases (WHO, 2005). This lancet series and WHO publication called for urgent, co-ordinate political and stepwise health system action to reduce impact of chronic diseases. It refuted common misunderstanding that act as barriers to action (Beaglehole et al. 2011).

A global team of scientists under the independent umbrella of the Chronic Disease Action Group produced a series of papers in 2007, 'The case of urgent global action' (Horton, 2007). This series focused on 23 countries responsible for 80% of burden in LMICs. They also identified cost effective interventions for prevention of chronic diseases: tobacco control and salt reduction, together with combined drug treatment for people at high absolute risk of CVD. The series call for action from all stakeholders, especially development agencies, donor countries and private foundations (Beaglehole and Horton, 2010).

Recently, NCDs were judged to be a developmental issue. The failure to address the chronic disease crisis was considered to be political failure rather than a technical failure, given that proven cost effective interventions are available (Geneau et al. 2010). It was emphasised that discussion on development should also include the underlying societal determinants of diseases and interrelationships between chronic disease, poverty and development for advancing the prevention of chronic diseases (Beaglehole and Horton, 2010).

Countries from Caribbean community called for a high level response from the UN due to managing high levels of diabetes and unaffordable treatments. The UN General Assembly adopted resolution on prevention in 2010. This resolution called for a high level meeting of the General Assembly in September 2011 with the participation of heads of state and government, on prevention and control of NCDs which is a historical point in global fight against NCDs epidemic. The premise of summit was that political interest at the domestic level was weak and solutions would benefit from international cooperation. The political declaration that followed framed NCDs as an important economic and development issue (Chand, 2012).

With the effort of bringing prevention and control of NCDs at the global health platform and its recognisation as an important health issues in developing countries, recent works on NCDs focused on developing policies and strategies for prevention and control of NCDs in LMICs. Various reports and research papers highlighted the availability of cost effective interventions for NCDs at both population as well as at individual level (WHO, 2005; Lim et al. 2007). These reports and papers emphasise the combination of both levels of intervention as part of a comprehensive strategy that serves the needs of entire population and has an impact at the individual, community and national levels.

In the interest of promoting a unified political message and a common voice, the Lancet NCD Action group-an informal collaboration of academics, practitioners, and civil society organisations and the NCD alliance-comprising four key international organisations (Union for International Cancer control, International Union against Tuberculosis and Lung disease, International Diabetes Federation and World Heart Federation) proposed a shortlist of priority actions for NCDs- four population wide approaches and one for clinical services (delivery of essential drugs and technologies)

which are considered to be cost effective in low resourced countries. They are acceleration of tobacco control by implementing the WHO frame work convention on tobacco control to achieve a world essentially free from tobacco by 2040, where less than 5% of people use tobacco, reduction in salt intake to less than 5g (2000 mg sodium) per person per day by 2025 which will lead to lower blood pressure, aligning national policies on agriculture, trade, industry and transport to promote improved diets, increase physical activity and reduce harmful alcohol use by imposing tax. For treatment, universal access to affordable and good quality drugs for NCDs is proposed as an important issue for all countries (Beaglehole et al. 2011). According to Lim et al. 2007, the best evidence-based clinical approach for NCDs in LMICs is a multidrug combination for people identified opportunistically in primary care as being in high risk of CVD, or for patients who have already had a clinical event (Lim et al. 2007). It has been proposed that population wide interventions like tobacco control and salt reduction should be given priority for full implementations in all countries as they are directed towards whole populations and will have advantages over targeted strategies i.e. most people will be exposed to their positive effects, the costs of implementation are low, and those already suffering will also benefit (Beaglehole et al. 2011).

Freudenberg, (2011) noted that the real challenge is the power of industries that profit by promoting the products, lifestyles and policies that contribute to global spread of NCDs. He further stated that for meaning full action to reduce NCDs, it is necessary to shift the power away from the corporations to the governments (Freudenberg, 2011). It has also been argued that the above mentioned proposed strategies to address NCDs focus largely on adult interventions that have been adopted in developed societies, often with mix success (Hanson et al. 2011). World Health Organization's proposals for chronic disease have emphasized advocacy to improve recognisation of the burden of disease and to apply knowledge we already have from developed world (WHO, 2005). Miranda et al. (2008), in their review work on NCDs in low and middle income countries highlights limited evidence of successful implementation of these cost effective interventions in developing countries remain limited.

In national chronic diseases policies in South Asians countries, it becomes a common phenomenon to include interventions like lifestyle modification of diet, exercise and smoking targeted at individuals. However Evidence from their use in developed

countries showed disappointing result with failure to show any impact on mortality or morbidity (Ebrahim and Smith, 1997).

A contextualisation appropriate to their greater circumstances is being suggested to understand growing burden and successful prevention and control strategies in LMICs. For instance the process of rural out-migration and associated urbanisation and modernisation and their divergent degrees of economic development which is differed from the developed countries is a specific context which needs to be considered to prevent and control the growing problem of NCDs in LMICs (Miranda et al. 2008). Research findings from developed settings are not necessarily suitable to other contexts, thus local knowledge is essential instead of exporting tired and failed models of developed countries (Ebrahim and Smith, 2001).

Following sections of the chapter discusses NCDs condition in India with particular focus on diabetes burden, its care and management.

2.2 Non communicable diseases in India: Burden and risk factors

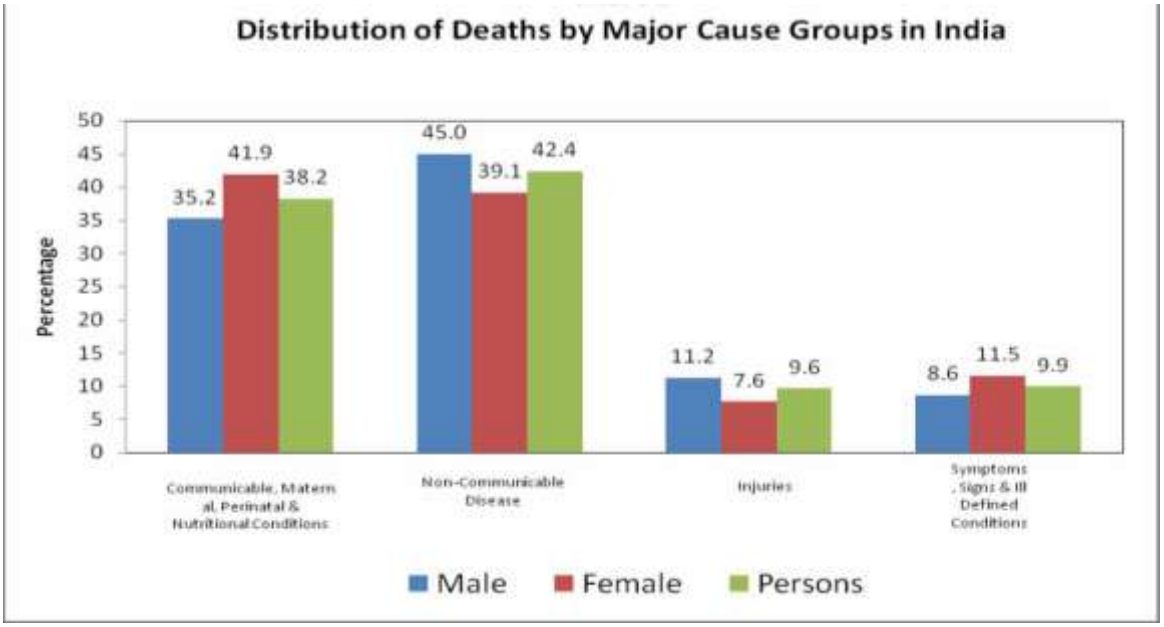
Due to economic liberalization, globalization, industrialization, urbanization and migration which are major trademark of Indian growth, the country has achieved significant progress in several economic, demographic and health indicators. Along with these changes, the changing health profiles with the emergence of non communicable diseases have brought major challenges in India. The paucity of nationally representative and standardized data for most NCD risk factors and diseases and most of the data available on regional level studies and urban area without a standardized definition to report study result has been reported as a challenge in analyzing magnitude of NCDs in India (Prabhakaran et al. 2011). However, national reports on burden and impact of non communicable diseases by ICMR and the National Commission on Macroeconomics and Health and several such independent research studies indicated the huge burden of NCDs.

According to Registrar General of India report on causes of deaths, NCDs are the leading causes of death in the country, constituting 42.4% of all deaths as shown in the figure 2.4 below. It is suggested that majority of ill defined causes are for older people (70 or higher age) and most of them are likely to be from non communicable diseases. The proportions of deaths due to NCDs are more in urban areas (56%) than

in rural areas. Over all leading causes of death was CVD (19%) followed by respiratory diseases (9%) (COPD, Asthma and others). Among the NCDs, cardiovascular diseases are number one cause of mortality (52%). NCDs account for more than two fifth (43%) of the DALYs and among this group cardiovascular diseases, diabetes, cancers together account for 40% of the NCD related DALYs in India (RGI, 2010).

Nearly 40% of hospital stays and 35% of all outpatient visits in 2004 was accounted to NCDs (Mahal et al. 2010). It is estimated that by 2030, 67% of all death in India will be due to NCDs (Leeder et al. 2004). This NCDs related death rate is reported to be higher among the poor and marginalised communities (Di Cesare et al. 2013). Regional studies have reported that even in rural India, the leading cause of death is NCDs (32%) followed by injuries and external cause of deaths (12%) (Joshi et al. 2006).

Figure 2.4: Distribution of death by major cause groups in India



Source: Reports on causes of Deaths, 2001-2003, Office of Registrar General, India 2010.

Mortality rates for people with age specific chronic diseases are estimated to be higher in India than in high income countries. In 2004, the overall age standardized mortality rates for chronic diseases were 769 per 100,000 men (56% higher than in high-income countries) and 602 per 100,000 women. Almost 60% of the disease burden in India is borne by people aged 15 years and older and in this age group, chronic diseases make up 62% of the total disease burden (Patel et al. 2011).

2.2.1 NCD risk factors and its changing patterns in India

Along with four major modifiable risk factors -tobacco use, harmful use of alcohol, physical inactivity and poor diet, hypertension, obesity, abnormal serum cholesterol and impaired glucose tolerance are identifies as leading risk factors for NCDs in India.

National Family Health Survey (NFHS-3) show that nearly 60% of men and 11% of women in India aged 15-49 use some form of tobacco in the year 2005-06 (IIPS, 2007). From 1998-2005, over a 7 years period, tobacco use had been increase among the younger (19% to 40%), richer (27% to 46%) and urban (34% to 50%) (Thankappan and Mini, 2008 as cited in Stuckler and Seigel, 2012). According to NFHS-3, (2005-06), 13% of adult women and 9% of men were found to be overweight and obese. It also reported that consumption of fruits and vegetables was low among the adults with 60-80% of them leading a sedentary life (IIPS, 2007).

Though NCD and its risk factors usually originate in the upper socio-economic strata, it is stated that they are diffusing across the social spectrum, with the social gradient ultimately reversing and the poor becoming predominantly afflicted. Few of the Indian studies have shown significantly higher morbidity and mortality among people with low income and education status often living in urban slums or rural parts of the country. The risk factors among the urban poor and middle classes are rapidly changing and increasing in India. According to a study 'Socio demographic patterning of non-communicable disease risk factors in rural India: a cross sectional study' by Kirna et al. (2010), Prevalence of risk factors for NCDs was high among different Socio demographic groups in rural India. Low intake of fruits and vegetables, tobacco and alcohol use, and being under weight were common in lower socioeconomic settings. Obesity, high cholesterol, men with diabetes, and women with hypertension were more prevalent in higher socioeconomic areas. Age increased the prevalence of

these risk factors and South Indians had more risk factors than North Indians (Kirna et al. 2010).

According to the report on India migration study group by Ebrahim et al. (2010), 41.9% of urban men and 37.8 % of migrant men were obese. In contrast, only 19 % of the rural men were obese. Similarly, 13.5% and 14.3 % of the urban and migrant men, respectively had diabetes, but it was only 6.2% for the rural men. The figures were similar for the women participants. The report also revealed the reversal of the social gradient whereby the poor suffer increased vulnerability to NCD risks and disease, a situation similar to that observed in developed countries that already have undergone health transition (Ebrahim et al. 2010).

A recent survey in Kerala reported one of the highest diabetes prevalence rates (14.6%) so far, in a rural setting (Vijaykumar, Arun and Kutty, 2009). A study from Chandigarh and Haryana found most CVD risk factors to be similar among those residing in urban and rural areas, indicating the increased vulnerability of the poor to CVD (Kar et al. 2010).

2.2.2 Current initiatives for NCD prevention and control in India

The healthcare system in India now has to address the rising threat posed by NCDs, in addition to the delivery of programmes for communicable diseases. Availability and quality of clinical care of NCDs is widely variable in India that there is huge inequalities in access to care among the high socio economic status individual with best care in tertiary hospitals to poor people with least or no access to even basic care causing delay in treatment or inadequate treatment which leads to complication, disability and mortality (Patel et al. 2011).

As a strategy to develop an integrated approach that target all major risk factors of CVD, Diabetes, cancer and COPD, Government of India initiated National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke (NPCDCS). In 2007, NPDCS was launched on a pilot basis in ten states (Assam, Punjab, Rajasthan, Karnataka, Tamil Nadu, Kerala, Andhra Pradesh, Madhya Pradesh, Sikkim and Gujarat). During 2010-12, it was implemented in 100 backward and inaccessible districts across 21 states focussing on strengthening of infrastructure, human resource development, health promotion and

early diagnosis, treatment and referral. Objectives of NPDCS are to prevention and control NCDs through behaviour and life style changes, early diagnosis and management, capacity building at various level of health care, train human resources within the public health set up to cope with increasing burden of NCDs, develop and establish capacity for palliative and rehabilitative care. These objectives are to be achieved through the strategies of health promotion, awareness generation and promotion of life style, early diagnosis through screening, timely, affordable and accurate diagnosis, access to affordable treatment, rehabilitation and monitoring and evaluation.[2]

In the recent past, some states such as Tamil Nadu and Kerala have independently implemented NCD prevention and control initiatives. The Tamil Nadu Health System Project (TNHSP) is an example. TNHSP successfully piloted clinic based NCD control interventions that are planned to be expanded to cover the whole state. In Kerala, the National Rural Health Mission carried out a pilot intervention programme for diabetes and hypertension in two districts providing screening and management services to the community with future plans to cover the entire state (Prabhakaran and Ajay, 2011)

A framework of recommended options and actions for NCD prevention and control at different levels of the healthcare system is also developed primarily for stroke, CVD and Diabetes. Different levels of services proposed are screening and diagnosis like non invasive screening (history, tobacco use, over weight/ obesity), identifications of signs and symptoms of acute stroke etc., management of acute/emergency cases (evaluation of hemodynamic status- BP, heart rate, heart failure), management of chronic care like tobacco cessation and follow up (Mohan, Reddy and Prabhakaran, 2011).

Challenge in NCD care is the nature of present health care system which focuses on treatment of acute conditions. Organisations of heath care services need to redirect for chronic diseases which need long term care and slow in progression. Therefore it is necessary to explore alternative integrated response to a continuum of ill health within

[2] http://pib.nic.in/release/release.asp?relid=63087&kwd= Accessed on 23rd January, 2013

a population that does not have tertiary care as focal point. Models which are developed for chronic care already are all based on primary health care system (Patel et al. 2011). WHO Innovative care for chronic conditions framework adapted from Chronic care model in 2002[3] was suggested of particular relevance to India's context. This framework identifies care building blocks to redesign health care systems in low and middle income countries to deal with long term heath conditions. It emphasises patients and families self care abilities, their interaction at the micro level; health care organisation and community and a well coordinated policy and health system environment

This present research work attempts to study interaction of patients and care givers with available health care services, care and management of their illness at individual, community and heath care organisation level using type II diabetes as a case study of chronic non communicable diseases. It aims to provide information on patients and care givers perspectives on diabetes care as well as health care provider's perspective which will be helpful for developing policy and strategy on primary health care system and chronic care models for effective non communicable diseases management. Following section reviewed literature on diabetes prevalence, risk factors and its care and management to find out the gaps in diabetes research.

2.3 Epidemiology of type II Diabetes

Diabetes is a life-long chronic metabolic disorder which is not often recorded as the cause of death. It accounts for only 4% of total NCDs mortality however it leads to other disease conditions which subsequently become cause of death and severe morbidities and premature mortality due to complications developed (ICMR, 2005). According to WHO study (Murray and Lopez, 1996), death indirectly attributable to diabetic is about 5 times more as compare to directly attributable in establish market economy. In India some retrospective hospital based study reported that infection is the major cause of death in diabetics followed by renal failure, coronary artery disease, cerebrovascular diseases and others in this order (Zarpar et al. 1999 as cited in ICMR 2005). Another study, Bhansali et al. (2003), also reported infection as main causes of death in diabetics followed by coronary heart disease, renal failure,

[3] http://www.who.int/chp/knowledge/publications/icccglobalreport.pdf , Accessed on 6th October 2013

cardiovascular and others in decreasing order. Diabetes itself is a risk factor for a number of NCDs. Following table shows the odd ratio/risk ratio and attributable risk associated with diabetes based on ICMR report on 'Assessment of Non Communicable Disease Burden in India'.

Table 2.1: Odd Ratio/Risk Ratio and Attributable risk associated with diabetes

Disease	Odd Ratio/Risk Ratio	Attributable risk
AMI	2.64	9.0
Cataract	8.55	32.0
Neuropathy	1.4	2.0
Stroke	1.7	4.0

Source: ICMR, Assessment of burden of Non communicable diseases: a project supported by WHO India office, 2005

The prevalence of diabetes is reported to be rapidly rising all over the globe in alarming rate (Huizinga and Rothman, 2006). Over the 30 years, the status of diabetes has changed from being considered as a mild disorder of the elderly to one of the major causes of morbidity and mortality affecting the youth and middle age people. Therefore keeping this background in mind, Diabetes is chosen for case study among other NCDs. Although there is an increase in the prevalence of type1diabetes, the major driver of the situation is the more common form of diabetes, namely type II diabetes which accounts for more than 90 % of all diabetes cases (Mohan et al. 2007).

2.3.1 Description, classification and diagnostic criteria of Diabetes

Diabetes Mellitus is a metabolic disorder of multiple aetiologies characterized by chronic hyperglycaemia with disturbances of carbohydrate, fat and protein metabolism resulting from defects in insulin secretion, insulin action or both. This disorder is frequently associated with long term damage which can lead to failure of organs like eyes, kidney, nerves, heart and blood vessels (WHO, 1999).

Diabetes is classified according to aetiological type. There are four main groups: Type I, Type II, gestational diabetes and others types. Most of the diabetes cases are type I

and II with type II diabetes as the most prevalent form accounting for 80% to over 95% of the cases in a population (Whiting, Unwin and Roglic, 2008, pp.78-79).

In type I diabetes as a result of destruction of the pancreatic beta cells by autoimmune or idiopathic process, insulin secretion is reduced or absent. It is usually diagnosed in childhood and accounts for around 5-10% of cases of diabetes in most population. More than 90% of people who developed type I diabetes carry known genetic marker for the disease. A type I diabetic person has to depend on exogenous insulin to sustain life. Total absence of insulin i.e when untreated, it will leads to ketoacidosis causing loss of consciousness and death without intervention. Type II is characterised by both a reduction in insulin action and a relative deficiency in insulin secretion. Its pathogenesis appears to involved complex interactions between genetic and environmental factors. It may represent with characteristics symptoms such as thirst, polyuria, blurring of vision and weight loss. In its severe forms ketoacidosis or non ketotic hyperosmolar states may developed leading to stupor, coma and in absence of effective treatment death. Often symptoms are not severe or may absent and consequently hyperglycaemia sufficient enough to cause pathological and functional changes may be present for a long time before the diagnosis is made ((whiting, Unwin and Roglic, 2008, pp.78-79). There are well defined biological and behavioural risk factors for type II diabetes. Most important of these are overweight and obesity particularly abdominal obesity, physical inactivity, dietary habits and smoking tobacco which are modifiable. Non modifiable risk factors are genetic, family history; low/high birth weight (Gupta et al. 2011) Gestational diabetes refers to diabetes that is first recognized during pregnancy (WHO, 1999). It is largely a form of type II diabetes. Around 90% of women with gestational diabetes return to normal glucose tolerance within a few weeks of delivery. But they are at markedly increase risk of developing type II diabetes over the coming years. It is also associated with the increase risk of the features like foetal death, malformation. Moreover babies from mothers with gestational diabetes appear to be at increased risk of type II diabetes and cardiovascular disease as an adult (Whiting, Unwin and Roglic, 2008, pp.78-79).

Diagnostic criteria based on ICMR guidelines on management of type II diabetes

Indication of person with diabetes:

- Symptoms of diabetes plus casual plasma glucose level of ≥ 200 mg/dl
- Fasting glucose ≥126mg/dl
- 2 hour post 75g glucose 200mg/dl

Table 2.2: Criteria for diagnosis of Diabetes and Glucose tolerance

Normoglycemia	IFG/IGT	Diabetes
FGT < 110 mg/dl	FPG ≥ 110 & <126 for IFG	FPG ≥ 126 mg/dl
2 h PG < 140 mg/dl	2h PG ≥ 140 & < 200 for IGT	2h PG≥200 mg/dl

FPG: Fasting Plasma Glucose; 2Hpg: 2 hour post load glucose test (Oral Glucose Tolerance), IFG: Impaired Fasting Glucose; IGT: Impaired Glucose Tolerance

2.3.2 Natural history of type II diabetes

Understanding natural history of type II diabetes is necessary for appropriate treatment. Development of type II diabetes is a continnum process starting from early asymptomatic phase with insulin resistance to mild postprandial hyperglycemia to full blown diabetes. Insulin resistance, nonautoimmune β cell dysfunction and inappropriately increase hepatic glucose production (HGP) are the triad of metabolic defects that characterized type II diabetes. When insulin resistance started first, β cell secret supraphysiological amounts of insulin to compensate for insulin resistance. This insulin resistance, compensatory hyperinsulinemia and mild postprandial hyperglycemia characterized IGT. Later on relative insulin deficiency occurs due to failure of β cell causing fast hyperglycemia and development of type II diabetes (Ramlo-Halsted and Edelman, 2000). As type II diabetes is a complex, multi-factorial and chronic in nature and associated with progressive deterioration of β-cell function and insulin resistance the individual is required to undergo different level of

treatment based condition of the disease, which depends on the level of the blood sugar. Significant of tight control of diabetes in preventing complications was shown in the United Kingdom Prospective Diabetes Study (UKPDS) and Diabetes Control and Complications Trial (DCCT).

Although insulin treatment is effective, its long-term use can lead to gains in fat mass, especially abdominal obesity, which may worsen insulin resistance. Moreover, repeated episodes of hypoglycaemia may cause major problems and with prior and proper Lifestyle modification and therapeutic intervention, the duration of progression from IGT to Diabetes and its complications can be prolonged (Ramachandran et al. 2010).

2.3.3 Global morbidity and mortality associated with diabetes

It has been highlighted that rise in prevalence is seen in all the six inhibited continents of the globe (Mohan, 2007). According to IDF, Diabetes atlas, 7th edition, one in eleven adults has diabetes in which one in two with diabetes is undiagnosed. In 2015, 415 million people have diabetes; by 2040 this will have risen to 642 million. The number of people with type II diabetes is increasing in every country with 75% of people with diabetes live in low- and middle-income countries. The greatest numbers of people with diabetes are between 20 to 64 years of age. Though type I diabetes is uncommon compare to type II, it is still increasing by 3% every year among children. There are about 15.6 million more men than women with diabetes (215.2 million men vs. 199.5 million women). This difference is expected to decrease to about 15.1 million more men than women (328.4 million men vs. 313.3 million women) by 2040. Currently there are more people with diabetes in urban (269.7 million) than in rural (145.1 million) areas. In low- and middle-income countries, the number of people with diabetes in urban areas is 186.2 million while 126.7 million live in rural areas. It is estimated that close to half (46.5%) of all people with diabetes around the world are not aware of their diseases (IDF, 2015).

Table 2.3: Proportion and number of people (20-79 years old) living with diabetes who are undiagnosed

IDF region	Proportion undiagnosed	Number of undiagnosed people with diabetes
Africa	66.7%	9.5 million
Europe	39.3%	23.5 million
Middle East and North Africa	40.6%	14.4 million
North America and Caribbean	29.9%	13.3 million
South and Central America	39.0%	11.5 million
South-East Asia	52.1%	40.8 million
Western Pacific	52.1%	79.8 million
World	**46.5%**	**192.8 million**

Source: Adapted from International Diabetes Federation, Diabetes Atlas, 7th edition, 2015, pp. 56

2.3.4 Studies on prevalence of diabetes in India: Review of Literature

Increasing prevalence among the younger age group, increasing out of pocket expenditure, rising rate of complications, rise in prevalence of risk factors and also Pre-diabetes, delayed diagnosis, limited health care facilities, sub optimal diabetes control are some of the challenges posed by type II diabetes in India (Ramachandran et al. 2013).

Estimated prevalence rates for urban as well as rural India, different geographical regions, years of study and authors are summarized in the following tables. And these are based on national survey as well as individual studies. Most of the literature review here are of type II diabetes.

ICMR conducted the first National study on prevalence of type II diabetes in India between 1972 and 1975. Screening was done in about 35,000 individuals above 14 years of age, capillary blood glucose level > 170 mg/dl as criteria to diagnose diabetes. The prevalence was 2.1% in urban population and 1.5% in the rural population while in those above 40 years of age it was 5% in urban and 2.8% in rural areas (Ahuja,1979).

Subsequent studies showed a rising trend in the prevalence of diabetes across different parts of India. In 1988, a study conducted at urban population in south India by Ramachandran et al. reported a prevalence of 5% (Ramachandran, 1988). A prevalence of 2.8% was reported in a national rural diabetes survey conducted between 1989 and 1991 in different parts of the country in selected rural populations (Sridhar, Rao and Ahuja, 2002). The Eluru survey which study the prevalence of known diabetes in four villages in Andra Pradesh showed a prevalence of 6.1% in individuals aged above 40 yr (Rao et al. 1989). In 1988, a study in Chennai reported a prevalence of 8.2% in urban and 2.4% in rural areas. A subsequent study in the same urban areas which was done after five years showed an age standardized prevalence of 11.6% indicating a rising trend in prevalence of diabetes (Ramachandran et al. 1992 &1997). According to a study in Thiruvanathanpuram in Kerala State in the year 1990, a very high prevalence 0f 16.3% was reported (Kutty, Joseph and Soman, 1999). In the same year, a prevalence of 8.2% was reported from Guwahati (Shah et al, 1999). The prevalence of known diabetes among adults aged >40 yr was found to be 1.9% in the Kashmir valley in 2000 (Zargar et al. 2000).

A population based study conducted in six metropolitan cities across India; The National Urban Diabetes Survey (NUDS), 2001 reported that age standardized prevalence of type II diabetes was 12.1%. The prevalence was higher in the southern part of India-13.5% in Chennai, 12.4% in Bangalore and 16.6% in Hyderabad compared to eastern India (Kolkata), 11.7%; northern India (New Delhi), 11.6% and western India (Mumbai), 9.3% (Ramachandran et al. 2001). A study conducted in western India by Gupta et al. 2003 among the urban population show age standardized prevalence of 8.6%. In rural Maharashtra, a high prevalence of 9.3% was reported (Doe et al. 2006). A community bases cross sectional study done in urban areas of Ernakulum district in Kerala, the Amrita Diabetes and Endocrine Population Survey (ADEPS) reported a high prevalence of 19.5% (Menon et al. 2006).

A systematic review on trends in diabetes epidemiology in India reported that based on available literature, prevalence of diabetes, IGT, IFG was increasing over years though it is slower in rural areas than urban areas. Studies included in this review are from different regions of the country (Sen et al. 2015). In the following tables, studies on prevalence of diabetes from different regions are presented. ICMR-INDIAB, a national wide study by ICMR to collect reliable data on diabetes is currently

Table 2.4: Prevalence of diabetes in urban cities of India

Place	Year	Author	Area	Prevalence (%)
Kashmir	2000	Zagar et al. 2000	North	6.1
New Delhi	1972	Ramachandran et al. 2005	North	2.3
New Delhi	1991	Ramachandran et al. 2005	North	6.7
New Delhi	2001	Ramachandran et al. 2005	North	10.3
New Delhi	2005	Ramachandran et al. 2005	North	15.0
Mumbai	2001	Ramachandran et al. 2001	West	9.3
Jaipur	2003	Gupta et al. 2003	West	8.6
Guwahati	1999	Shah et al. 1999	East	8.3
Kolkata	2001	Ramachandran et al. 2001	East	11.7
Thriuvanathapuram	1999	Raman et al. 1999	South	16.3
Hyderabad	2001	Ramachandran et al. 2001	South	16.6
Bengaluru	2001	Ramachandran et al. 2001	South	12.4
Chennai	2001 2006	Ramachandran et al. 2001 Mohan et al. 2006	South	13.5 14.3
Ernakulam	2006	Menon et al. 2006	South	19.5
Vellore		Raghupathy et al. 2007	South	3.7
Tamil Nadu	2008	Ramachandran et al. 2008	South	18.6
India	2001	Sadikot et al. 2004	NA	5.6
Multi centric	2008	Mohan et al. 2008 (WHO)	Multi centric	7.1
Pondicherry	2009 2011	Gupta et al. 2009 Bharti et al. 2011	South	8.3 12.0
Ahmadabad	2011	Nayak et al. 2011	West	13.8
Chandigarh	2011	Ravikumar et al. 2011	North	11.1

Source: Gupta (2011) & Sen et al. (2015).

Table 2.5: Prevalence of diabetes in rural areas, India

Place	Year	Prevalence (%)	Author
Delhi	1991	1.5	Ahuja MMS 1991
Punjab	1994	4.6	Wander et al. 1994
Srinagar	2000	4.0	Zargar et al. 2000
India	2001	2.7	Sadikot et al. 2004
Rajasthan	2004	1.8	Aggarwal et al. 2004
Mysore	2005	3.8	Basavanagowdappa et al. 2005
Maharastra	2006	9.3	Deo et al. 2006
Nagpur	2007	3.7	Kokiwar et al. 2007
Vellore	2007	2.1	Raghupathy et al 2007
Tamil Nadu	2008	9.1	Ramachandran et al. 2008
Multi-centric	2008	3.1	Mohan et al. 2008
Aurangabad	2009	1.7	Todker et al. 2009
Alappuzha, Kerala	2009	12.5	Vijayakumar et al. 2009
Tamil Nadu	2010	6.0	Gupta et al. 2010
Central Maharashtra	2010	5.6	Jonas et al. 2010

Source: Gupta (2011) & Sen et al. (2015)

undergoing in phase wise. ICMR recently published a report on first phase conducted at three states Tamil Nadu, Maharashtra, Jharkhand and a union territory Chandigarh. This report showed that weighted prevalence of diabetes (both known and newly diagnosed) in Tamil Nadu was 10.4%, Jharkhand-5.3%, Chandigarh-13.6% and Maharashtra-8.4%. The prevalence of pre diabetes was 8.3%, 8.1%, 14.6% and 12.8% in Tamil Nadu, Jharkhand, Chandigarh and Maharashtra respectively. Except in Chandigarh, the prevalence of pre diabetes was higher in urban areas in all age groups (ICMR, 2016).

Data based on NFHS-3 (2005-6) suggested that Type II diabetes prevalence in rural India is higher in Kerala, Tripura, West Bengal, Goa and Sikkim (1500 to >2000 individuals per 100,000 individuals) and least in central India (<500 individuals per 100,000 individuals) (IIPS, 2007).

Undiagnosed diabetes cases: Studies have shown high prevalence of undiagnosed diabetes in the community. ADEPS study in Ernakulum district of Kerala reported 10.5% of undiagnosed diabetes whereas know diabetes prevalence was 9.0% (Menon et al. 2006). CURES study also reported higher number of undiagnosed diabetes (9.1%) than known diabetes cases (6.1%) (Mohan et al. 2006). Another study on Kashmir valley showed the prevalence of undiagnosed diabetes as 4.25% and known diabetes as 1.9% (Zargar et al. 2000). Such unknown diabetes cases results to early complications such as micro vascular as well as macro vascular complications.

Complications: Long-standing diabetes mellitus is associated with an increased prevalence of micro vascular and macro vascular diseases which are the real burden of diabetes. It is responsible for 9% of acute myocardial infections, 4% of stroke cases, 2% of neuropathy and 32% of cataract cases. This reflects independent contribution of diabetes to various NCDs. Since the risk factors clusters more often rather than individually, the contribution of diabetes in combination with other risk factors would have more serious dimensions (ICMR, 2006).

According to Chennai Urban Population study (CUPS) among the diabetes cases prevalence of coronary artery disease was 21.4% while with normal glucose tolerance cases it was 9.1% (Mohan et al. 2001). A follow up of the original CUPS cohort showed that mortality due to cardio vascular (diabetic subjects: 52.9% vs. Non diabetic subjects 24.2%, P=0.042) and renal (diabetic subjects 23.5% vs. Non diabetic subject s: 6.1%, P=0.072) was higher among diabetic subjects (Mohan et al. 2006). The prevalence of peripheral vascular disease (PVD) was 6.3% among diabetic subjects compare to 2.7% in non diabetic subjects (Premalatha et al. 2000). A population based study reported that the prevalence of overt nephropathy was 2.2% and microalbuminuria was present in 26.9%. Glycated Haemoglobin, duration of diabetes, systolic blood pressure was independently associated with diabetic nephropathy (Mohan et al. 2007). Diabetic foot infections are a major problem and a common cause for hospital admission of diabetic patients in India. Although the prevalence of PVD is low, neuropathy is very common and is an associated risk factor for foot infections, which often tend to recur (Vijay, 2000 as cited in Ramachandran, 2007a).

Prevalence of diabetes was found to be lower in the low socio-economic group living in urban areas compared with the high income group (12.6% vs. 24.6% in subjects > 40 years). However, due to inadequate control of diabetes, the long term complications such as coronary artery diseases were higher in the low socio-economic group. This was to some extend related to the higher rates of risk factors such as uncontrolled diabetes, high cholesterol, hypertension, smoking and alcohol consumption (Ramachandran, 2007a).

2.3.5 Causes of diabetes in India

Interaction of several modifiable and non modifiable risk factors which includes unhealthy diet, physical inactivity, smoking, use of alcohol, family history, genetic, body mass index (BMI), greater waist circumference and waist to hip ratio along with changes in environment where we live such as urbanisation, globalisation is suggested as causes of diabetes (Mohan et al. 2007). In the context of raising prevalence in India genetic predisposition is considered as high risk factor among Asian Indian.

'Asian Indian Phenotype' – a certain unique clinical, biochemical characteristics of Asian Indian ethnic groups is considered to be strong factor contributing to increasing rate of diabetes among this group. Greater waist circumference, waist to hip ratio despite having low BMI leads to greater degree of central obesity increasing to insulin resistance (Joshi, 2003; Deepa et al. 2004; Raji et al. 2001). Studies suggested and confirm that 'Thin fat phenotype', 'the thin fat Indian baby[4]' in neonates persisted in childhood and this could be a precursor of the diabetogenic adult phenotype (Yajnik, 2002; Yajnik et al. 2003). These findings suggest that Asian Indians are more exposed to diabetes and related metabolic disorders because of their genetic predisposition (Krishnaveni et al. 2005). Recent findings by Yagnik et al. (2003) has suggested an intrauterine origin of central adiposity and hyperinsulinemia in Asian Indians. He has reported that Indian babies born in an urban society in India (Pune), despite being lighter in weight compared with white babies, had comparable sub-scapular skin-fold thickness and higher cord blood

[4] The thin fat Indian baby refers that Indian babies are born smaller but relatively fatter compared to Caucasian babies (Yajnik et al. 2003).

leptin and insulin concentrations are at higher risk to develop diabetes later in adulthood. This study reiterates the evidence in addition to the Barker's hypothesis[5].

Fast food culture, sedentarinism, migration which is important characteristics of urbanisation, modernisation and globalisation are considered as main drivers of diabetes epidemic in India. Neel's 'thrifty genotype hypothesis[6]' is another way to explain explosive increase of diabetes among Asian Indians. This hypothesis proposes that some genes are selected over others to allow survival in times of famine by efficiently storing all available energy during time of feast. When expose to high energy diet these same genes can lead to obesity and type II diabetes. With increasing availability of high energy fast food, decreasing physical activity due to increase in opportunity of occupation which are mostly sedentary resulted in fast increase of diabetes and obesity in less than a generation (Mohan et al. 2007). Migration from rural areas to urban slums in metropolitan cities in India brings mark changes in social and cultural changes which led to obesity, glucose intolerance and dyslipidaemia (Misra et al.2001).

Mohan et al. (2007) stated that as the epidemic matures and reaches the next stage of transition, incidence of diabetes and CVD among rich and affluent section of the society will decrease as they will change their activity patterns and making healthy choices as demonstrated in other developed countries.

2.3.6 Socio economic burden and cost of care of diabetes

[5] Barker's hypothesis proposes that the epidemiological associations between poor fetal and infant growth and the subsequent development of type 2 diabetes and the metabolic syndrome result from the effects of poor nutrition in early life, which produces permanent changes in glucose-insulin metabolism. These changes include reduced capacity for insulin secretion and insulin resistance which, combined with effects of obesity, ageing and physical inactivity, are the most important factors in determining type 2 diabetes (Neel, Weder and Julius, 1998)

[6] The thrifty genotype hypothesis, addresses the etiology of diabetes and obesity. Neel proposed that predisposition to diabetes may arise because of genetic variations that were advantageous in certain environmental situations but were later rendered disadvantageous—and disease causing—in different environments. According to the thrifty genotype hypothesis, a predisposition to muscle insulin resistance may have protected individuals during periods of food deprivation by reducing muscle utilization of glucose and favoring glucose utilization in organs, such as the brain that operates through an insulin-independent mechanism (Neel, Weder and Julius, 1998).

Diabetes being a life-long disorder is an expensive ailment. It is estimated that the annual cost of diabetes care would be approximately 90,200 million rupees. The average expenditure per patient per year would be a minimum of Rs 4,500 (Shobhana et al. 2000). A study by Ramachandran, 2007, estimated annual expenses incurred by diabetes patients attending specialist centre and economically poorer section of the society attending government general hospital. For inpatient care patients 17.5% of their annual income was spent on diabetes care, 7.7% was spent in outpatient care and for those cases need surgery care, 16.3% of their annual income was spent as cost of care. All of these expenses were met by out of pocket by the patients (Ramachandran, 2007). In India, financial burden of care is shared by family and relatives, using money from family savings. The expenditure increases if the patients are hospitalized and further will be incurred if they need any surgery. Patients with diabetic complications or kidney complications required additional and continuing expenses for specialized care. A recent analysis has shown a further increased in expenditure to an average of Rs. 10,000 –per annum in urban areas and Rs. 6,260 per annum in the rural areas (Ramachandran et al. 2007).

Type I diabetic patients and patients with complications face additional economic burden. Although the amounts spend by the upper and lower class persons were similar, the percentage of the income spent was higher among the lower class, due to their low earning. The median percentage of income spent on diabetes was 22% for the entire group, varying from 59% in the low socioeconomic group, 32% in the middle socio-economic group, 18% in the upper middle income group and 12% in the high income group. Patients managed on an outpatient basis incurred an expenditure of 16% of income while 23% of income was spent on those requiring hospitalization (Shobhana, 2000).

It was found that diabetic patients without complications like foot problems spent Rs 4,373, which was similar to the above report. The expenditure on care of foot problems increased significantly, outpatient care requiring a median of Rs 7200 and in-patient care requiring Rs 16,910 in a year. This assumes great importance because foot complications are a major cause for hospitalization cost and morbidity and most of them are preventable (Shobhana et al. 2000). In India direct medical cost to identify one subject with insulin glucose tolerance is INR 5,278 (Ramachandran et al. 2007). The cost of insulin amounts to 350.00 USD per year (16,000 Indian rupees)

while medication for non insulin requiring patients cost about 70.00 USD (Shobhana & Ramachandran 2007). DEDICOM survey, a community based data available from the middle and high income groups in Delhi was analyzed by Kumar et al. (2008) to determine direct cost of ambulatory care, to evaluate association of socio economic status and spending and also the quality of care. It was found that a significant portion of family income was spending on diabetes related care (Rs. 6000 per year). The cost is higher for subjects with longer duration of diagnosis and with higher education or income, those with co morbidity and requiring Oral hypoglycaemia agents and insulin (Kumar et al. 2008).

From the above section on review of literature we can highlight the increasing trend of diabetes prevalence in different regions of India, both in rural as well as urban areas with large number of undiagnosed diabetes cases which is almost double of known cases. It further reveal that late diagnosis and treatment lead to early development of complications and this again causes high expenditure on treatment and surgery. Cost of care is incurred by patients out of pocket expenditure and financial burden is often shared by family members and relatives spending money from family savings or selling valuable assets of family. This situation highlights that in India, we need to developed strategies on how to deal with increasing number of diabetes cases and how can we successfully managed diabetes at individual level as well as whole nation. Therefore, in the following section literature on what are the diabetes care and management strategies in India, barriers and challenges in successful diabetes management are reviewed. Before this, concept and understanding on what do care and management mean in case of chronic illness like diabetes is presented.

2.4 Diabetes care and management

Diabetes mellitus being a chronic condition requires continue care and self management from the patients and care givers. Goal of diabetes care is not getting cure of but glycemic control and preventing from development of complications. Early diagnosis of diabetes cases is given emphasis for effective management. It has been indicated in many intervention studies that good metabolic control can delay or prevent diabetes complications and progression. With increasing focus on tight metabolic control as treatment goal, use of glycosylated haemoglobin (HbA1c) as

indicators and introducing home blood glucose monitoring devices contributed to change in approach to diabetes self care with a shift in more responsibility of patients (Collins et al. 2009; Grey and Thurber et al. 1991). Along with proper treatment advices and medications from the health care providers, adopting healthy lifestyle, changes in health behaviours and self management by patients are observed as basis for diabetes care (Nguma, 2010; Kadirvelu, Sadasivan and Ng, 2012).

The daily activities that individual undertake to keep their illness under control and minimize its impact on their physical health and functioning, as well as enabling them to cope with the physical and psychological squealae of their illness is referred as self management of chronic illness (Clarke et al. 1991). Self management of diabetes involves self monitoring of blood glucose, adjustment to dietary intake as well as insulin doses depending on blood glucose level (De Weerdt et al. 1999). Anderson et al. 1995 purposed that as much as 95% of diabetes self management is provided by the patients and their care givers (Anderson et al. 1995). Glasgow and colleagues also highlighted it is largely the responsibility of patients (Glasgow et al. 2001). These are complex activities and requiring the empowering of patients with diabetes care knowledge. This calls for the important role of diabetes management education not only to impart knowledge but also to provide practical skills on insulin injection, self monitoring blood glucose level (Watkins et al. 1996). Therefore providing adequate information on diabetes management to the patients and their care givers has been focussed. As Kadirvelu, Sadasivan and Ng (2012) pointed out that it is more than just an adherence to recommended sets of behaviour, food habit or medications, it involves deliberate decision making, problem solving with high level of control on the part of patients. It needs an individual motivation to self manage their disease (Peyrot and Rubbin, 2007) where the role of social support and family is important. According to O'Reilly (2005), it is important to allow patients to determine the involvement of others in their care and this emphasises the importance of involving family, a caregiver and/or social networks in the management of diabetes. Therefore, even with adequate know-how in diabetes care by patients themselves, management occurs in larger context of formal health care providers, informal social network members (friends, families and peers) as well as various socio economic and cultural factors (Kadirvelu, Sadasivan and Ng 2012; Anderson et al. 1995). A comprehensive

approach with the understanding of these larger factors would help in effective management of diabetes.

Peyrot et al. (2006) identified several important gaps in diabetes management across developed and developing countries (Asian and European countries). First, diabetes management is less than optimal and is often compromised by diabetes-related distress which is often not treated. Second, health care providers often lack a good understanding of the social and psychological problems that people with diabetes face. Thirdly, team care for people with diabetes is uncommon.

The Action to Control Cardiovascular Risk in Diabetes (ACCORD), a randomized multi-centric trial, conducted in the USA and Canada showed the warning signals to clinicians of the consequences of overaggressive treatment of type II diabetes especially in high risk group such as the elderly. It highlighted that the treatment goals should be individualized according to the patient's health profile and not all diabetic subjects should be aggressively treated (Couzin, 2008).

Based on these literatures we can say that diabetes care is more than consulting physicians and taking medicine. Due to its chronic nature and its goal of care that is keeping glycemic control rather than aiming for complete cure of illness, an individual suffering from diabetes has to live his entire life with this condition. Therefore, for effective care and management, role of individual, care givers, family and social network is considered important component. Diabetes patients and their physicians need to keep regular contact and it is necessary to have a clear understanding between them as diabetes patients face psychological and social problem which is often overlook in biomedical care but actually are important factor in effective diabetes management.

2.4.1 Diabetes management and care in India

Several studies have shown that diabetes treatment outcome in India is far from the optimal in spite of rising expenditure on diabetes care and quality of care is poor (Raheja et al. 2001; Nagpal and Bhartia, 2006). In a country like India with weak health services system, lack of health personal, scarcity of monitoring equipments and drugs especially in remote area made it difficult to manage ever growing burden of diabetes. Rao et al. (2002) highlighted that with seventy per cent of the population

live in rural India, easy access to primary services, transportation by ambulance to regional diabetes centres for further management is required to meet the diabetic patient's requirements and ensure easy approach to the health centres (Rao et al. 2002). Health care delivery in India is heterogeneity with free medical care offered by government run institutes and private health care providers where patients have to spend from their own pocket. In such context, there are evidences that show low and middle income group of patients prefer private health care facilities even though there is high expenditure causing financial burden (Ramachandran, 2007).

In spite of increasing burden of diabetes in India, health systems have not kept pace in evolving mechanisms to tackle diabetes effectively and the result is reflected in the sheer number (50-60%) of people with diabetes who do not achieve the glycemic target of glycated hemoglobin (HbA1c) below 7% as reported in the limited studies available on diabetes care in India (Deepa et al. 2011).

Rao, Presek and Metello (2002) suggested setting up diabetes health care centres in rural areas in India as most of the people live in rural areas, poor and illiterate to ensure easy accessible and approachable to health centres by patients from the periphery. This study emphasised to prioritise establishment of diabetes care services within the public health care system as it would lessen the economic burden of diabetes care by patients, family members and whole society. They so suggested that primary health care must play a key role in offering continuous, comprehensive and co -ordinates care for chronic diseases like diabetes with diabetes health care teams which comprises of diabetologists, nurses, educator and dieticians.

Global evidences showed that awareness strengthens nation policies and health outcomes and a health system strengthening approach with standards of care at all levels, nationally accepted management protocols and regulatory framework are acknowledged as crucial in good diabetes management (Verma, Khana and Bharti, 2012; Kumar, 2011).

During the seventh five year plan, 1987, Government of India started the national diabetes control program on pilot basis to some districts of Tamil Nadu, J&k and Karnataka with the objective of detection of high risk individuals, early intervention through health education, early diagnosis of cases, appropriate treatment, prevention and slow down the progression of complications, provision of equal opportunities for

physical attainment and scholastic achievement for the diabetic patients and rehabilitation of those partially or totally handicapped diabetes people. Due to the paucity of fund this program could not be extended to other states.[7]

Ministry of Health and Family welfare and Public Health Foundation of India started Healthy India.org, a new website advocating healthy living and the prevention of diabetes and other NCDs[8]. In 2005, Ministry of health conducted a national level consultation to 'identify action pathways and partnership for implementing the global strategy in Indian context'. In January 8th, 2008 National Programme for Prevention and Control of Diabetes, Cardiovascular Diseases and Stroke (NPDCS) was launched as described in detail in above section. It has the objective of risk reduction for prevention of NCD and early diagnosis and appropriate management of these diseases. The expected outcomes are awareness generated on healthy life styles, health promotion at school, community and work places and decease in the incidence of NCDs[9]. Although NCDs programme was implemented due to various challenges in ground level, it still has to go long way to provide continnum of care for chronic diseases (Verma, Khana and Bharti, 2012).

With the strategy of shift in health care responsibility to community health workers and patient led self management various regional level diabetes care programs are increasing in India. WHO collaborating Centre for Diabetes which is located at Chennai is actively engaged in the primary prevention of diabetes, childhood obesity and other related disorders by promotion of health and reduction of risk through the individual and on community basis. Two approaches for the prevention of diabetes are population approach which aims to bring about important changes in the health of a large percentage of the population by promoting healthy lifestyle and high Risk approach by identifying those who may be at higher risk, measurement of risk and

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http://nihfw.nic.in/ndc-nihfw/html/Programmes/NationalDiabetesControl.htm , Accessed on 7th July, 2014

[8] http://www.healthy-india.org/ Accessed on 7th July, 2014

[9] Ministry of Health and Family Welfare, Govt. Of India, National Programme for Prevention and Control of Cancer, Diabetes, Cardio vascular Disease and Stroke: Broad guidelines, 2013.

intervention to prevent the development of diabetes (Gupta, 2011; Albeti, Zimmet and Shaw, 2007).

Chunampet rural diabetes prevention program, an innovative for prevention and management of diabetes in India was set up by Diabetes research foundation in Chennai with the support of World diabetes foundation and Indian space research organisation.[10] In this program rural diabetes care centres are set up in the village to provide basic diabetes care. Village health workers and telemedicine units are used for screening diabetes cases and complications. Patients pay fees in subsidised rate and those cannot pay get free treatment. For complicated cases needing surgery, they are referred to tertiary care. This provides a model to deliver preventive and therapeutic care for diabetes in rural areas (Patel, 2011).

Targeting pre-diabetes for life-style interventions is also another approach. In consultation with WHO in 2003, ICMR conducted a workshop for the development of guidelines for the management of Type II diabetes. There are also other programs initiated by Diabetes Foundation of India (Private NGO) like MARG (The Path) which focuses on primary prevention with the aim of creating awareness about diabetes, obesity, lipid disorder and heart diseases in children and adolescent in North India. Another project is CHETNA, 'children' Health Education through Nutrition and Health Awareness' which aim to impart health education on prevention of obesity, diabetes and heart diseases in school children (Gupta, 2011).

2.4.2 Awareness and knowledge of diabetes management

Over all awareness and knowledge of diabetes patients, care givers and general population is one of the important factors in successful diabetes management. Lack of knowledge in signs and symptoms is often cited as reason for delay in diagnosis and treatment. It has been highlighted that not only are there huge number of people with diabetes in India but awareness levels are also low. The CURES reported that awareness about diabetes in urban areas is extremely low with nearly 25% of population unaware of a condition called diabetes. Only 22% of the population and 41% of known diabetic subjects felt that diabetes could be prevented. Among the

[10] http://mdrf.in/telemedicine.html , Accessed o 14th November 2014

known diabetic subjects, only 40.6% were aware that diabetes could lead to some organ damage. Even among self-reported diabetic subjects, knowledge about diabetes including awareness of complications of diabetes was poor (Deepa et al. 2005). This indicates that majority of the patients have not been taught about diabetes by their physicians.

According to a population based study conducted by Murugesan et al. at a city in southern India, 2007 reported that knowledge regarding causes of diabetes, its prevention and methods to improve health was significantly low among the general population. Less than 30% of the study population knew about complications related to kidneys, eyes and nerves and nearly half of the diabetic subjects felt it was temporary phenomenon (Murugasan et al. 2007).

A study conducted at rural Tamaka village of Kolar revealed that knowledge regarding diabetes, risk factors, long term complications, self care, monitoring blood sugar level and visiting doctors at regular basis are very poor in rural areas (Munninarayana et al. 2010). A study by Kaur and others in Chandigarh observed that 63.3% of them were poor in practicing foot care through regular washing, monitoring of blood sugar was infrequent (46.7%) (Kaur et al. 1998).

It has been highlighted that results of these studies represent only the tip of the iceberg, in-depth community based studies has to be undertaken to assess the awareness, about diabetes and community level awareness programs need to be launched to increase awareness (Munninarayana et al. 2010).

The Diabcare-Asia Study carried out in 1998, to investigate the relationship between diabetes control, management and late complications in a subset of urban Indian diabetes population treated in 26 tertiary diabetes care centres revealed the need for efforts to increase awareness amongst health professionals to improve diabetes care in India (Joshi et al. 2008).

A national based study conducted by ICMR in four different regions Tamil Nadu (south), Maharashtra (west), Chandigarh (north) and Jharkhand (east) reported that overall only about 50% of the population of the four regions of India studied have heard of a condition called diabetes. A significant disparity exists in the level of knowledge of diabetes between the different regions studied. In rural areas, the

awareness and knowledge about diabetes are significantly lower than in urban areas. Females had low awareness rates compared with males in all regions except Chandigarh. Not surprisingly, there is better knowledge of diabetes among the self-reported diabetic population compared with the general population in all four regions studied. However, even among known diabetic subjects, knowledge levels are not satisfactory. Based on a composite knowledge score, among the population studied, Tamil Nadu had the highest and Jharkhand the lowest score, while among self-reported diabetic subjects, Maharashtra had the highest and Tamil Nadu had the lowest score (Deepa et al. 2014).

Lau et al. conducted a survey on diabetes awareness, risk factors and health attitude of rural community at Khowai district at west Tripura which is the first rural survey for diabetes in North East India. This study population had a low baseline knowledge and awareness about diabetes, despite significant diabetes prevalence of 9% (Lau et al. 2009). A community bases study in rural Arunachal Pradesh conducted using STEPs questionnaires reported low diabetes awareness among the study population (21%) (Singh et al. 2012).

These literature on diabetes awareness show that there is lack of knowledge reasons for which is act as barrier in successful diabetes management by delaying in diagnosis and treatment seeking. However unlike the general assumption, better knowledge do not necessarily lead to better treatment seeking behaviour and better health outcomes. It is necessary to explore nature of health seeking behaviour, what triggers the patients to seek care and factors influencing the decisions of behaviours and practices.

2.4.3 Concept of health seeking behaviour in diabetes care

Health seeking behviour is influence by many factors. Baru (2005) stated that iseaeses are not only about physiological and pathological aspect but also it has social dimensions that it dislocats a sick individual and family in emotional, social and economic level. So knowledge and perceiveing the severity of symptoms alone is not the only factor in inlfiuencing health seeking behaviour. These above mentioned social dimensions interact with availability, accessibility and responsiveness of health care institutions influencing health seeking behaviour of a population (Baru, 2005, pp. 47).

When individuals perceive themselves to be ill or have health problem, they undertake activities to find appropriate solution to their health problem s and this is refer as health seeking behaviour (kasl and Cobb, 1966 as cited in Nguma, 2010). MacKian states that health-seeking behaviour concerns factors which enable or prevent people from making 'health choices' in their lifestyle and in their use of medical care and treatment (Nguma, 2010). Mechanic (1977) states that 'varying perceptions, feelings and acts affecting the personal and social meaning of symptoms, illness, disability and their consequences' (Baru, 2005, pp.46).

Kleinman (1988) argues that meaning and experience of an illness is embedded in the complex of personnel, socio economic and political nexus. Works of Anderson et al (1991) and Brittan and Maynard (1984) showed that experiences and illness behaviour and meaning are determined by the material context, social relation, restructuring of life and structural constraints (Anderson 1991; Brittan and Maynard 1984 as cited in Soman, 1997). Banerji (1982) showed the health culture in rural Indian context and it is rooted in the socio-economic realities. Reducing concept of diseases to biological sphere, by abstracting it from its social framework would lead to ignoring of social conditions (Knowles, 1997 as cited in Yadavendu, 2005).

Health-seeking behaviour is specifically a response to perceived ill-health and it should be looked at within its cultural context, since it and related activities are influenced by culturally recognised signs and symptoms and their associated interpretations (Nguma, 2010).

Another study conducted among urban poor in Chennai (Devrajan, 2013) on social dimentions of coping among type II diabetes patiens demonstrated the concept of 'felt need' among the patients and responsiveness of health care providers as determinants of 'multiple resort pattern' in seeking health care of diabetes.

The process of seeking treatment from different sources and changing doctors and health care institutions is also reported in a study by Goenka (2002) among the diabetes patients of Delhi. She identified this behaviour as patinets and care givers way of seeking better treatment and explianed this process in different 'trajectories of patient movemnets'. It highlights that patients behaviour of different treatment seeking process and non adherence has to be located within the specific context rather than completely focusing on individual behaviour. This specific context comprises of

patients own perception, knowledge and skills obtained from experiences of living with diabetes, their social network, environmental context, structural issues related with health care services and provider's responsiveness.

Hjelm et al. (2011) revealed in their study on health seeking behaviour on diabetes in Uganda that living conditions including heath care organisations, individual's belief and gender are important determining factors in health seeking behavior. Perceived failure in health care to manage diabetes or related complications led many, particularly women, to seek alternative treatment from complementary and alternative practitioners in the folk sector.

A study conducted in Scotland highlighted everday living experience of diabetes patients in thier social context, their priority in ldaily life and their perception influence their decision on adherence to diabetes regime within a structural context. Their decision and course of actions were justified and explained as being benefit to them in that particular time, within his or her concept of benifit (Drummond and Manson, 1990).

A study on health seeking behaviour among the urban poor in Dar es Salaam, Tanzania provides an insight into how living with diabetes in a resource constraints environment has major implications in health seeking behaviour leaving people with few choices which lead to poor consequences to diabetes managemnt (Kolling , 2010).

2.4.4 Challenges and barriers in Diabetes Care

Several studies have shown various challenges and barriers in diabetes care which include patient barriers, social barriers, barriers related to health system and medical professionals. Patient related barriers identified are lack of awareness, poor motivation, economic constraints, denying risk, stress, fear, confusion, immediate benefits not seen, lack of family and social support, lack of trust in health care providers and changing behaviour. Social barriers identified in urban areas are changing patterns in the lifestyle in families, unhealthy eating habits, e.g. fast foods, frequent eating out, faith in different systems of treatment and frequent changes in treatment. For rural areas barriers identified are high rates of illiteracy, poverty and different socioeconomic strata, multilingual population, cultural, religious and

customs, superstitions and beliefs, faith in alternate systems of treatment, hesitancy to go to doctors or hospitals. Barriers related to health system and medical professions are medical training focused to acute care, treatment of acute diseases more rewarding to doctors, most of the clinical workload in developing societies is due to acute illnesses and infection, even nurses find acute illness treatment more paying, cost of having a team for diabetes management, lack of trained paramedical, lack of health care infrastructures and technologies (Ramachandran et al. undated).[11]

Scarcity of health care institutions, lack of manpower, diagnostic tools, and poor availability of medicines especially in remote areas made practical management of diabetes in developing country more difficult (WHO,1989). This issue of non availability, inaccessibility in diabetes health care service is even more complicated by poor knowledge and awareness of people on diabetes care and complications causing late diagnosis with many complications which patients and family have to spend large amount of money.

National NCD submit on 'strengthening policies for diabetes care' discussed challenges on implementation of NCD programs in pilot districts of NPCDCS. These challenges are as per experiences of health care providers working on the ground to implement pilot programs to manage NCDs. Major Challenges identified were Lack of adequate centres and means for procuring and dispersing the medical drugs and equipments on time , lack of means to monitor the supply of the drugs and equipments, lack of qualified medical professionals for health care centers , limited Reach- how to dispense the diagnosis and treatment to the rural population , lack of accountability and monitoring of the medical staff- how to ensure that proper care and facilities are reaching the masses ,lack of awareness- how to create awareness amongst the population where the majority is illiterate, lack of uniform education material & training- how to ensure that the all the medical functionaries are given

[11] http://www.apiindia.org/medicine_update_2013/chap40.pdf , Accessed on 22nd June 2014

proper, correct and uniform training[12]. This highlights the barriers and challenges related to organisational and heath care system.

In a survey of clinical diabetologists conducted through a semi-structured questionnaire in India, poor awareness among physicians (22.7%), western guidelines being not applicable to Indian patients (22.7%) and cost to patients (18.2%) were some of the barriers identified (Hasan , Zodpey and Saraf, 2012).

The IMPROVE Control India Study (ICI) which was conducted with 452 clinicians in 8 metropolitan cities of India. This study showed that though insulin therapy is accepted as one of the most effective and dependable treatment option, there is several barriers to its usage among type II diabetes cases particularly the acceptance of Insulin therapy. Other reported barriers are irregular monitoring of diabetes status and lack of standardization of laboratory techniques ect. The average patient's perception of being in good control of diabetes was the fact that he/she complied with medication, diet, exercise plan and that they did not feel any untoward symptoms, too few of them knew target blood glucose or HbA1c values as measure of control of their diabetes (Joshi et al. 2008).

Literatures have shown patients non adherence to diabetes treatment, care and management practices such as not following recommended life style, diet, physical activities, discontinue of taking medication or insulin use hinder successful management of diabetes (Venkataraman, Kannan and Mohan, 2009; Wangnoo et al. 2013).

A qualitative study conducted at community level in Tunisia reported that financial barrier was mostly mentioned as patient factor, poor patient compliance to diet adherence, medications, blood tests and referrals were also highlighted. According to patients and paramedical staff dietary compliances was most relevant problem whereas doctors mentioned problem of medical compliance often. Clinicians often cited poor education background of patients as hindrance in successful care. As for the health care related factors, many doctors mentioned that lack of motivation of

[12] http://www.gramvaani.org/wp-content/uploads/2013/06/Strengthening-Health-Care-Policies-through-Technology2.pdf Accessed on 14th April, 2016.

health care provider, lack of nurses, dieticians, specialist as well as primary care doctors are barriers. Organisational factors were lack of availability of medication, HbA1c testing facility, and routine diabetes check up such as eye examination in primary care setting (Alberti et al. 2007).

2.4.5 Traditional medicine and diabetes care

Traditional medicines refers to practices and approaches that apply separately or in combination of plants, animals, mineral based medicines, spiritual practices, manual techniques and exercises to diagnose, prevent and treat illness or maintain or enhance well being (Awah, 2006). Traditional system of medicine has been recognised by WHO in third World Health Assembly in the year 1977 and had passed resolutions supporting the utilization of traditional medicine practitioners in government sponsored health care system. In India, AYUSH has been part of the mainstream health care system (Guite, 2011). In order to meet primary health care need millions of people around the world used traditional medicine (Awah, 2006). It is estimated that nearly 70% of population in India use traditional medicine and traditional form of health care provided by healer to meet the community felt needs in which modern or western medicines do not meet (Lavekar and Sharma, 2005; Mankazana, 1979 as cited in Ningombam et al. 2014). Guite (2011) stated in her book on indigenous medicine and health care in Manipur that there are many cultures specific living tradition of its own local medical system in India which are community supported. This folk medicinal stream is located in the villages of rural India and there are no tribal or rural community without a local health traditions, a system which is local resource based relying on locally available flora, fauna and minerals. Because of its vast knowledge, natural resources available and human resources, folk traditions could bring together to achieved the goal of self sufficiency in primary health care (Guite, 2011, pp. 3). In north eastern part of India, studies have documented on rich traditional medicine knowledge among different ethnic communities and it has been practicing since inmemorable times. Even though traditional healing practices have been declining with the availability of modern medical facilities especially in urban areas, traditional healers are still common and act as primary care providers for various illnesses (Ningombam et al. 2014; Ramashankar, Deb and Sharma, 2012). It has been reported in various studies across different countries like Uganda (Rutebemberwa et al. 2013; Atwine et al. 2015; Hajelm and Atwine, 2011),

Zimbabwe (Hjelm and Mufunda, 2010), India (Modak et al. 2007), China (Jung et al. 2006), Kenya (Mwangi and Gitonga, 2014), that use of traditional medicine or herbs for diabetes management is quite a common phenomenon.

A study of health seeking behaviour in Uganda (Hajelm and Atwine, 2011) and another study on complementary alternative medicine use among Indian community in South Africa (Singh, Raidoo and Harries, 2004) reported use of traditional medicines as a response to perceived failure of treatment of diabetes by allopathic health care, in these studies diabetes patients first consult with physician in the professional sectors (as described by Kleinman) and if they feel that their symptoms and illness are not getting better then they go to seek treatment from the local healers in folk sector .

A study conducted in Kenya by Mwangi and Gitonga (2014) reported no influence of gender in used of traditional medicine however education status had influence in use or not use of traditional medicines with those in higher education using more. An independent association with complementary and alternative traditional medicines use has been shown in Malaysians with a higher educational level and income (Hassan et al. as cited in Hajelm and Atwine, 2011). Study on indigenous medicine and health care among a tribal group in Manipur, North east India reported that utilization of indigenous medicine has nothing much to do with education as the majority believe in it (Guite, 2011).

Studies by Atwine et al (2015), Hajelm and Atwine (2011) and Nguma (2010) in Uganda and Tanzania showed that influence of friends and family (known as popular sector according to Kleinman's work on health seeking), healers, affordability, easy availability influences patients to seek care from traditional healers and their treatment seeking pattern is not consistent with frequent changes of health care provider such as from modern medicine to traditional healers. They suggested that health care professionals should be aware about the potential harm this health seeking behaviour can have on diabetes care and strategies should be developed to initiate health interventions that includes and consider the perspectives of patients popular sectors (family, friends and relatives), professional sectors (modern health care providers) and folk sector (traditional healers).

2.4.6 Peer support and social support in diabetes care

Peer support refers to use of non professionals who have diabetes and those with close familiarity with its management to assists patients in managing their own health. This echoes the fact that peer support has been recognized as a central strategy for successful empowerment approach to diabetes care by providing social and emotional support, and act as a link to clinical care (Kadirvelu, Sadasivan and Ng, 2012).

World Health Organisation has recognised peer support as a promising approach to diabetes management[13]. It reported that peer support occurs formally as part of diabetes education programs and as informally among the friends and families living with diabetes giving support and other advices. The central premise for engaging patients in their chronic disease management as peer support is that because of having same experiences and fighting to overcome same challenges, they can offer much support in term of knowledge, emotional and expertise. As daily decision on diabetes care is almost made by individual living with it without much help from health care providers, their support to other patients is of great value (Wientjens, 2008).

Others studies on peer and social support also highlighted about emotional support patients gain from peer network. It has been reported that in diabetes care, both friends and families were important sources of support and strong family support predicted good self management. Individual motivation to self manages their disease is critical for effective self management which may be influenced by factors- disease and treatment related, demographic and psychological in which the role of social support is vital and one of the important issue (Peyrot et al. 2007). Studies conducted by Schiotz et al. (2012) reported that frequent contact with friends was associated with fewer psychological problems, more positive assessment of care and health, promoting self management behaviours such as frequent exercising and foot examination. It offers emotional support in the form of cognitive support, involving the provision of information, knowledge and advice as well as offer of material support (Jaconsen , 1986).

[13] www.who.int/diabetes/publications/en Accessed on 28th April, 2016.

It is suggested that the social network of the patients provides a substantial part of the information that a patient receives on the diagnosis, treatment, complications and expectation of diabetes (Winocour, 2002). Such support would foster feelings of comfort and alter the perceived stress and physical reactions that the patient endures (Kadirvelu, Sadasivan and Ng, 2012).

Various research have shown that people living with diabetes have so much to offer to each other, peer to peer interventions are in demand by patients, they are being widely used in New Zealand and appear to be of quantitative benefits in primary prevention (Simmons , 2010). It has been shown by initiatives such as United Kingdom's Expert Patient Programme that peer support can be a promising approach to increasing the quality and quantity of support (Donaldson, 2003). Peer support can complement and enhance other health care services to help people follow management plans in daily life, stay motivated, and cope with the stressors of chronic disease, and at the same time stay connected to their health care providers to get the care they need, often in cost-effective manner (Oftedal et al. 2010). It can be a constant link for people living with a chronic disease or condition, that there is sharing of knowledge and experience that the others (including many health workers) do not have, as well as providing practical and emotional support for behaviour change (Solomon, 2004).

A study on social support by Wallhagen (1999) examined that support may be supportive or non-supportive, depending on how it is delivered, how it is viewed, and the context within which is provided. Another work by Kahn (1994) revealed 'support in other words, can consists of teaching, encouraging, and enabling another person, but it can also take the form of constraining, warning against, and doing for another'.

Lack of proper training, feedback, supervision and support of peer workers are identified as potential barriers in peer support especially when it is not accepted or acknowledged by the health system (Kadirvelu, Sadasivan and Ng, 2012).

2.4.7 Coping with diabetes and impacts on life of family members

Lazarus and Folkman described two major types of coping—problem-focused and emotion-focused. Problem-oriented coping aimed at solving the problem and likely to use when the individual accept the stressor and agree to change. For a person with diabetes, problem-oriented coping strategies may be used in managing difficult eating

situations. Emotion-focused coping is most useful when the individual appraises the experience as one for which nothing can be done to modify the event or stressor, or when the stressor is transitory and will resolve itself. Avoidance, minimization, distancing, and finding positive value in negative events are some of the strategies use in this coping style. For some patients with diabetes, adolescents in particular, avoidance of managing diabetes (not performing blood glucose testing or administering injections) provides a way of coping with the emotional distress of being different from one's peers and not all of these approaches are positive coping strategies in terms of both psychological and medical outcomes (Grey, 2000).

Kleinman's work coping with chronic illness highlights that meaning of successful coping is uncertain in any generic sense apart from an individual's particular experience in a particular local context. Struggle to cope with the illness is done on a daily basis by patients, care givers, family members and even health care providers. Ongoing process of chronic care in which personal problems constantly emerge challenges the technical control, social disorder and individual mastery (Kleinman, 1988).

A study by Collins et al. (2009) characterised self coping strategies within the paradigm of self control/determination and self efficacies. Three self coping strategies were identified: proactive manager who independently take care of themselves, practice self care and closely in touch with health care practices, passive follower with consistent in self care practices but dependent on other and family members or health care providers and lastly non conformist who do not follow self care practices and management, who are not motivated enough, denial and perceived that their health is out of their control. All patients cannot be grouped into these categories distinctively as they were not static.

A study conducted among aboriginal women and men with diabetes in Canada and their coping indicated various themes on coping such as interdependence and interconnectedness of social network, family support providing a space for sharing feelings and issues, spirituality to facilitate symbolic healing, enculturation establishing reconnection to cultural values and tradition. Another theme of coping is self care and self control practices to deal with their condition and expressing it an appropriate way (Iwasaki, Bartlett and O'Neil, 2005). Another study in Ghana also

reported religious and cultural approach to coping with stress of diabetes, medical coping keeping regular contact with health care providers (Korsah, 2015).

Kleiman (1988) stated '...the family often is a major player in the illness drama'. Like the patients learnt to live as chronic cases, care givers also learnt to treat patients with keeping the view of chronicity. Each family member like patients make sense of their experience and come to terms with it.

Living with a diabetes patient in a family is often described as 'living with emotional roller coaster' with full of worries related to their present as well as future life (Rintala, Paavilainen and Kurki, 2013).

2.5 Conceptualisation of the study

From the literature we can highlight that goal of diabetes care and managements are focused on early detection, monitoring and modifying risk factors of diabetes, glycemic control, slowing the progress of complications. To achieve these goals important measures acknowledged are 'healthy living, lifestyle' to achieved desirable glycemic level through diet control, exercise and proper medications, regular monitoring for development of complications. Because of this understanding globally as well as in India prevention and management initiatives of both government as well as NGOs focused on life style changes and dietary habits. Patient led self management has been focused as core strategy of the management of chronic disease (Patel et al. 2011).

As indicated by literature on diabetes, it is predominantly treated as medical problem and subjective experience of diabetes is often neglected. The main focus of diabetes management come from the medical understanding and practices which emphasizes the physiological disease and dysfunction while separating the illness experiences in the social context. This disconnected between 'two fundamentally different ways of conceptualizing threats to own health and well being' remains as research gaps. Current literature shows that most of the strategies for diabetes are focused more on need of adopting healthy life style.

Tight glycemic control and slow down the progress of developing complications is major goal in diabetes management which is to be achieved by medication, diet control and exercise: known as three pillars of diabetes management regime

(Canadian Medical Association and Canadian Diabetes Association, 1098). It is often indicated that out of these three regimens health provider's job is to prescribe suitable medications only. It is the responsibility of the patient and their care giver to live a healthy life style adopting diet chart, physical activities and compliance to medications as prescribed by the providers.

However within the current social context Diabetes is most prominently situated as clinical experiences and personal experiences of deficiency. In the clinical experiences a diabetes person's adjustment and agency is considered as essential. Considering a patient's own perceptions of diabetes and discovering patients personal needs are more effective for successful management. Literature suggested the need for diabetes researchers to investigate how well diabetes experience is understood by providers and patients (Drummond and Manson, 1990).

Current perspective of studying diabetes as a clinical /medical problem might lead to over medicalization of diabetes care. Long term care of chronic diseases like diabetes goes beyond the traditional boundaries of medicines and single sector responsibility, involving care givers and patients (Bal, 2000). There are medico social implications in the need for long-term care for chronic diseases. One major goal of diabetes care is to achieve a condition of well being in the presence of chronic disease and often disability. In this context harmful effect of medicalising chronic care need to be recognized (Jenning et al. 1988 as cited in Bal, 2000). It has been highlighted from the experiences of developed countries that such medicalisation increases health care cost without meeting the non medical need of the people and accessibility of health care services for chronic diseases like diabetes has been uneven. The actual use of various services is shaped more by economic possibilities, political environments, culture and prevailing welfare philosophies than by needs and choices of individuals (Bal, 2000). In the context of India, this might be more serious due to social factors like poverty, illiteracy, traditional beliefs and existence of multiple disciplines of medicine.

In India, management of patients with NCDs show the feature of heterogeneity with patients receiving the best possible evidenced based care and treatment in tertiary hospitals to patients who have poor or even no access to basic care (Karthikeyan,2007 as cited in Patel et al. 2011). Health expenditure was higher with most spent on private sector services than on public sector. People in lower income groups spending

more than higher income group (70% of monthly income on chronic care and 45% for those in the highest income group (Blarajan, Selvraj and Subramanian, 2011).

Studies conducted in India have shown the increasing cost of treating NCDs such as diabetes particularly in urban households. In response to reduced central funding and restricted opportunities for states to raise more money for public funding of health services, Indian hospital services have become an investment opportunity for corporate and multinational enterprises and strong health insurance market (Purohit, 2001). It is suggested that without independent assessment and regulation, the vested interests of the corporate enterprises will probably determine both the diseases that receive attention and the cost to individuals and the government (Patel et al. 2011).

In such situation, emphasis within the chronic disease care continues to be on predominantly specialist, curative and tertiary care with private and informal health-care sectors as the main providers of care in most low-income and middle-income countries (Beaglehole et al. 2008). This may lead to less attention to primary prevention strategies and more preference to secondary and tertiary models of hospital care which are more profitable. In most countries, technology for treatment of complications of NCDs like diabetes takes precedence over investment towards effective control of the causes of the complications (Bal, 2000). When the health care system is unregulated and services are provided by various sources, private, public or charity, the rise of NCDs in an opportunity for private pharmacy companies and market for NCDs related technologies especially in developing countries (Chand, 2012).

It may lead to a technology oriented approach and a philosophy of aggressive treatment of individual patient without meeting the patients psychosocial needs (Bal, 2000). Such techno centric approach treats health as a purely individual or personal, biological phenomenon whose problems are to be solved at the individual level through medical technologies. For successful intervention, management and care of ill health, it is, therefore, necessary to further explore the broader perspectives of people's perceptions, needs and social realities. Above and all, the problem patients or people faces lies within the complexity of whole social system and dynamics that constitute the matrix of their existence (Sagar, 1999). It has been suggested that studies from the patient's perspectives with an emphasis on management and care

practices are important in order to understand and unfold the complexity of causes and potential conditions for better diabetes management at a subjective, inter subjective and structural level (Kolling et al, 2010). In health care, this problem is further complexes by the dynamics of available health care services, providers and social realities of the patient's life. This calls for a social determinate frame work in understanding and studying diabetes care and management among the patients.

Here, in this present study social dynamic is defined as- interaction of technology oriented, aggressive treatment approach of available health care services and providers with patients within their own social context and perspective on diabetes.

A research on 'increasing urbanization in Tribal states of North East India: Implications for the prevalence of chronic diseases' by Khongsdier (2008) made an attempt to examine the increasing urbanisation in north eastern tribal states and its nutritional and health consequences with special reference to NDCs. This paper emphasised that increasing prevalence of NCDs are the products of complex biological and cultural interactions of human populations in relation to biotic and physical environment in time and space. Therefore, formulating of research questions with attention to cultural dimensions, socio economic and urban rural differences in health risks and chronic diseases ought to be an important contribution to management of NCDs (Khongsdier, 2008). Therefore in this framework, this research work aimed to study the social dynamics of NCDs care and management through a case study of diabetes care and management in Manipur.

2.6 Pre Pilot study

A pre-pilot study was conducted at Thoubal district, Manipur to obtain a broad insight into how diabetes is perceived and managed. Discussions were carried out with concerned officials, doctors, civil society organisations which were working at health related issues and some diabetic patients. According to the discussion with service providers, a large number of people are coming to the hospital with diabetes related symptoms as well as with complications from all sections of the society, valley and hill regions. Many of the patients were opportunistically diagnosed. They felt that diabetes is becoming an important health issue at Manipur and expressed the need of primary level care. Patients changing their consultant physicians quite often, lack of

continuity of care, irregular monitoring of sugar level, lack of awareness, ignorance of patients are some of the issues highlighted by providers.

However, patients expressed their feelings of unnecessary, repeated diagnosis, treatment and drugs prescriptions. They talked about high cost of medicines and diagnosis in which their consult doctors usually refer them to private diagnostic laboratory adding more cost. Some patients felt that self care and restriction in their food habit is much more effective in controlling their sugar level than aggressive treatments of doctors. There is also practice of using locally available medicinal plants.

It was found out that, at Sub division Kakching of Thoubal district; diabetic patients of the region have established an organisation 'Diabetes Self Care Society' in the year 2002. It was started with the motive of sharing information and knowledge of diabetes like self care, food they should avoid, which hospital and doctors to consult, different signs and symptoms of complications. They organised health camps, screening for sugar level, awareness campaign and also distribution of medicines in collaboration with pharmaceutical companies such as Lupine, Indo co, Nova Nordisk. They have not received any assistance from the state. Members find it useful not only in technical assistance but also as emotional and psychological support.

On the basis of literature reviewed and the findings from pre-pilot study, the following are some of the issues identified: patients need and preferences, barriers and difficulties in treatment seeking, self care and management in the context of their socio-economic and everyday life, patients' society and activities in diabetes care and management and perspectives of providers. Therefore, this research work proposes to examine the social dynamics of diabetes in relation to management, treatment and care at individual, community and professional level.

2.7 Research questions:

What are the factors influencing diabetes care and management the patients and care givers? How do patients and care givers in different social context and background interact with available diabetes care services and health care providers in the study area?

1. What are knowledge and perceptions of diabetes care and management among patients and care givers in the study area?
2. What is the health seeking behaviour and self care practices of patients and care givers in diabetes care?
3. What are barriers and challenges in diabetes care faced by patients and care givers?
4. What are the coping strategies and how does their experiences of living with diabetes impact their life and self care activities?
5. What are the perspectives of health care providers in diabetes care and available diabetes care services in the study area? How their perspective influences diabetes care?
6. How can a patients network 'diabetes self care society' provides a platform for social support in diabetes care?

2.8 Objectives

The broad objective of the study is to examine the social dynamics of diabetes care and management of the patients with different socio context and their interaction with different forms of service provisions available in the district such as the district hospital, private clinics and self care society of patients.

1. To study knowledge and perception on diabetes care among the patients and care givers of different socio economic background
2. To study health seeking behaviour and self care practices on diabetes care
3. To study barriers and challenges in diabetes care
4. To study experiences of living with diabetes, impact on life of family members and coping strategies in their everyday life and social context
5. To study service providers' perspective on diabetes care and management of patients and available services in the study area
6. To explore the concept and ideas behind the establishment of Diabetes patients network 'Diabetes self care society' in the study area and to study its activities.

In the next chapter three, research methodology employed in this thesis to answers these questions and attained the objectives is presented.

CHAPTER 3

Research methodology

The purpose of this research work is to study knowledge, perspectives and health seeking behaviour among diabetes patients and care givers as well as perspectives of health care providers, to understand factors influencing care and management practices. This chapter describes the methodology used to achieve these objectives. This includes following topics such as study design, study setting, pilot study and recruitment strategies of respondents, data collection tool, procedure and analytical process. The methodology of this research work includes various sub studies which was developed over the study period and it uses qualitative research design. Qualitative research method was used in this study to obtain in depth information on perspectives, self care practices and lived experiences of diabetes patients. Findings are presented by using descriptive and interpretative analysis of the responses supported by narratives.

3.1 Rational for using Qualitative research design in diabetes care study

Qualitative research design was adopted for this research work which aimed to provide in depth information on patients, care givers and health care providers perspective on diabetes and its care, how their own understanding and experiences of living with diabetes and available heath care services influences diabetes care and management practices.

Health care delivery particularly, diabetes care has to be understood in its natural environments, context and complex interactions of various factors and what each symptoms and factors are meant to patients and care providers (Goenka, 2002). Qualitative research study things in natural settings, emphasis on understanding a phenomenon from its own perspectives, attempt to bring out the phenomena in terms of meaning people brings to them or making sense of or to interpret the phenomena (Danzin and Lincol, 2005, p. 3; Elliot, Fisher, Rennie, 1999). Qualitative research methods play a major role in developing a science of "evidence based implementation". This aptly recognised in a BMJ editorial entitled "why do

qualitative research?" it should begin to closed the gap between the science of discovery and implementation" (Jones, 1995).

In the area of health service research, qualitative methods are considered as appropriate to find out why a particular interventions or available health care services are not effective. By getting into the depth of the situation or problem as usually done by using qualitative research, it will help in improving health care delivery (Goenka, 2002).To many medical scientists, qualitative research may seem as unscientific and anecdotal but as critiques point out, Medicine itself is more than just application of scientific rule (Green and Britten, 1998). Not only it able to study areas where quantitative research is not able to access such as lay health belief, qualitative research is prerequisite of good quantitative research especially those field of study where there are little previous investigation (Pope and Mary, 1995).

Flick (2009, p. 12) give the following rational on relevance of qualitative research and special need of such approach in the current situation on his textbook on qualitative research:

> *Qualitative research is of specific relevance to the study of social relations, due to the fact of the pluralisation of life worlds. Key expressions for this pluralisation are the "new obscurity" (Habermas 1996), the growing "individualisation of ways of living and biographical patterns" (Beck 1992), and the dissolution of "old" social inequalities into the new diversity of milieus, subcultures, life styles, and ways of living.*

The author further explained that due to this diversification of life worlds social researchers have to constantly deal with new social contexts and perspectives. Therefore they are increasingly forced to use the inductive strategies in their research which requires 'sensitizing concepts' for approaching context to be study rather than starting the studies from a theory and testing them. As the current research work intended to explore the in depth understanding of social dynamics in diabetes care by studying the patients and their care givers and their interaction with different forms of health care services in their social context, qualitative research was chosen as a strategy of choice. A deeper understanding of the experience of the patients, care givers and behaviour of health care providers who treated patients with diabetes will be allowed by qualitative research methods. This research method aided in

discovering and understanding the context in which decisions, actions and events occurred.

3.2 Study setting

3.2.1 Thoubal District, Manipur

The study was conducted in Thoubal district, Manipur. It is one of the States in the North Eastern part of India with a population of 27, 21, 756 which is increased from figure of 22.49 lakh in 2001 census. The ratio of the urban-rural population is approximately 3:7 which is better in term of urbanization as compared to rest of the north-eastern states. Geographically, the state of Manipur could be divided into two regions viz, the hill and the valley. The valley lies in the central part of the state and the hills surrounded the valley. The hill regions comprises of 5 districts, Senapati, Ukhrun, Tamelong, Chandel and Churachandpur. The valley region consists of 4 districts, Imphal east, Imphal west, Bishenpur and Thoubal. Hill districts occupy about 90% of the total area of the state and the valley occupies only about $1/10^{th}$. One of the important facets in the state is highly lopsided geographical distribution of population with a substantial chunk of population concentrated in valley. Almost all urban centres are in the valley with the hilly area being rural in character. Population density of the valley area is over 15 times higher than the hilly areas. It is multi ethnic, multi language and multi religious state comprising of the Meiteis (majority ethnic group), Pangans (Manipuri Muslims) who live in the valley, surrounding hilly areas are inhibited by the Nagas, Kukis and few other ethnic groups. Christianity, which was introduced by the British, was embraced only by the hill tribes. The Meiteis follow Hinduism and schedule caste population of the state are also under the Meitei ethnic group.[1]

According to 2011 census, literacy rate of the state is higher than the national average (79.85 per cent vs. 74.04 per cent). Male literacy rate is 86.49 per cent and for female, it is 73.17 per cent (Census of India, 2011). In spite of high education rate, Manipur

[1] Manipur.nic.in/glance.html, Accessed on 14^{th} August, 2015

remain as one of socio economically backward state as compare to rest of the country. Economy of the state is characterised by high rate of educated unemployment, poverty, low capital formation, inadequate infrastructural facilities, geographical isolation, communication bottlenecks and practically no industrialisation. Agriculture continues to be the mainstay of the economy, with more than 70 per cent of the population dependent on it for livelihood. This situation is further aggravated by ethnic conflicts, social differences and chronic problem of insurgencies prevailing in the state (Sharma, 2016).

As development of a state is one of the determinants of the health of its people, lack of the health care infrastructure, human as well as material resources could be related to the backwardness of the state having a huge impact on health status of the people. Most of the available health care facilities are unevenly distributed with major, specialist hospitals and doctors are all located in urban centres especially in capital city, Imphal (Guite, 2011, p.5). Along with these issues, unique culture, social norms, food pattern, way of living influences the health characteristic and health seeking behaviour of the people. Such lack of health care facilities are often compensated by folk/traditional healers. Although, less well documented, the use of traditional medicines and consultations with traditional healers who practices herbal remedies or person who has inherited the gift of healing or mystic incantation (magical formula or spiritually allegorical) is widely acknowledged in Manipur (Ningombam et al, 2014). Such unique cultural and social norm provides a different picture in studying health care practices of the people.

According to NHFS 4, 2015-16, Random blood sugar measurement conducted among the adults of aged 15 to 49, prevalence of diabetes in men was 9.3% and for female, it was 7.6% as shown in the table below.

Table 3.1: Random Blood sugar level among adults (15-49 years), Manipur, 2015-2016

		Urban	Rural	Combine
Women	Blood sugar level high (>140 mg/dl) (%)	8.8	6.8	7.6
	Blood sugar level very high (>160 mg/dl) (%)	3.7	2.6	3.0
Men	Blood sugar level high (>140 mg/dl) (%)	9.1	9.4	9.3
	Blood sugar level very high (>160 mg/dl) (%)	4.0	4.5	4.3

Source: NFSH 4, 2015-2016, Manipur state profile

3.2.2 Health services in Manipur: Manpower and infrastructure

The State has per capita one of the highest concentrations of Health Manpower among the North-Eastern States. There are two tertiary Health Care Centres (Two Medical Colleges Regional Institute of Medical Sciences (RIMS) and Jawaharlal Nehru Institute of Medical Sciences (JNIMS) and their attached hospitals),7 District Hospitals(against 9 districts in the State).Further there are 26 private Hospitals and Nursing Homes which are registered under the "Manipur Nursing Home and Clinic Registration Act.1992".

The recent mushrooming of private hospitals in and around Imphal was cited as one of the major causes for migration of specialists from State Service resulting to acute shortage of specialists in the district hospitals and Community Health Centres (CHCs). Moreover, quite a number of specialist doctors are also employed in the hospitals and medical colleges outside the State. As on December 2012 there were 862 doctors serving under the State Heath Department of which 117 are specialists. The number of medical doctors in the State Health Department plus those employed in RIMS and JNIMS together is 1333. Further, there are 172 doctors employed in the

"Private Hospitals and Nursing Homes" in the State. Accounting all the doctors in public as well as private service, doctor population ratio of the state is around 1 doctor per 1635 population, without counting the number of AYUSH doctors. The number of MBBS seats provided by the Government was around 50 annually which have jumped up to about 135 from 2010-11 with the inception of JNIMS a State Govt. owned medical college in Imphal East District.[2]

3.2.3 Health infrastructures

Following table 3.2 provides information on health institutions available in the state. According to Directorate General of Health Services, by counting the number of beds available in private institutions along with state health institutions and RIMS (under union government), it may be said that desirable number of bed population ratio is achieved. However, the issue remains with the quality of these infrastructures. Many of them are not functioning properly due poor infrastructures and maintenance. These are specially can be seen in state run CHCs, PHCs and even in District hospitals. Above these health institutes, big hospital, specialists, laboratories and advance medical facilities are unevenly distributed and concentrated in urban areas only.

3.2.4 Thoubal district: A brief profile of the main study area

Thoubal district occupies the bigger portion of the eastern half of Manipur valley. The district has three sub divisions- Lilong, Thoubal and Kakching as highlighted by different colours in the following figure 3.1. It has community development block in each sub division. Total urban population is 35.48%. As per census of 2011, the district has the second highest sex ratio of 1026 next to 1029 of Imphal east (Thoubal.nic.in/about/html, accessed on September, 2015). Hindu and Muslim are the two major religious group of the district consisting of 61% and 24% of the total population respectively. Share of the Christian population is just about 2 %.

Agriculture is the most important source of livelihood for the people of the district. More than 70 per cent of the total population of the district is directly or indirectly depended on agricultural activities. Handloom which is a traditional activity and sericulture are other source of income. Women are mainly involved in handloom

[2] www.manipurhealthdirectorate.in, Accessed on 14th August, 2015

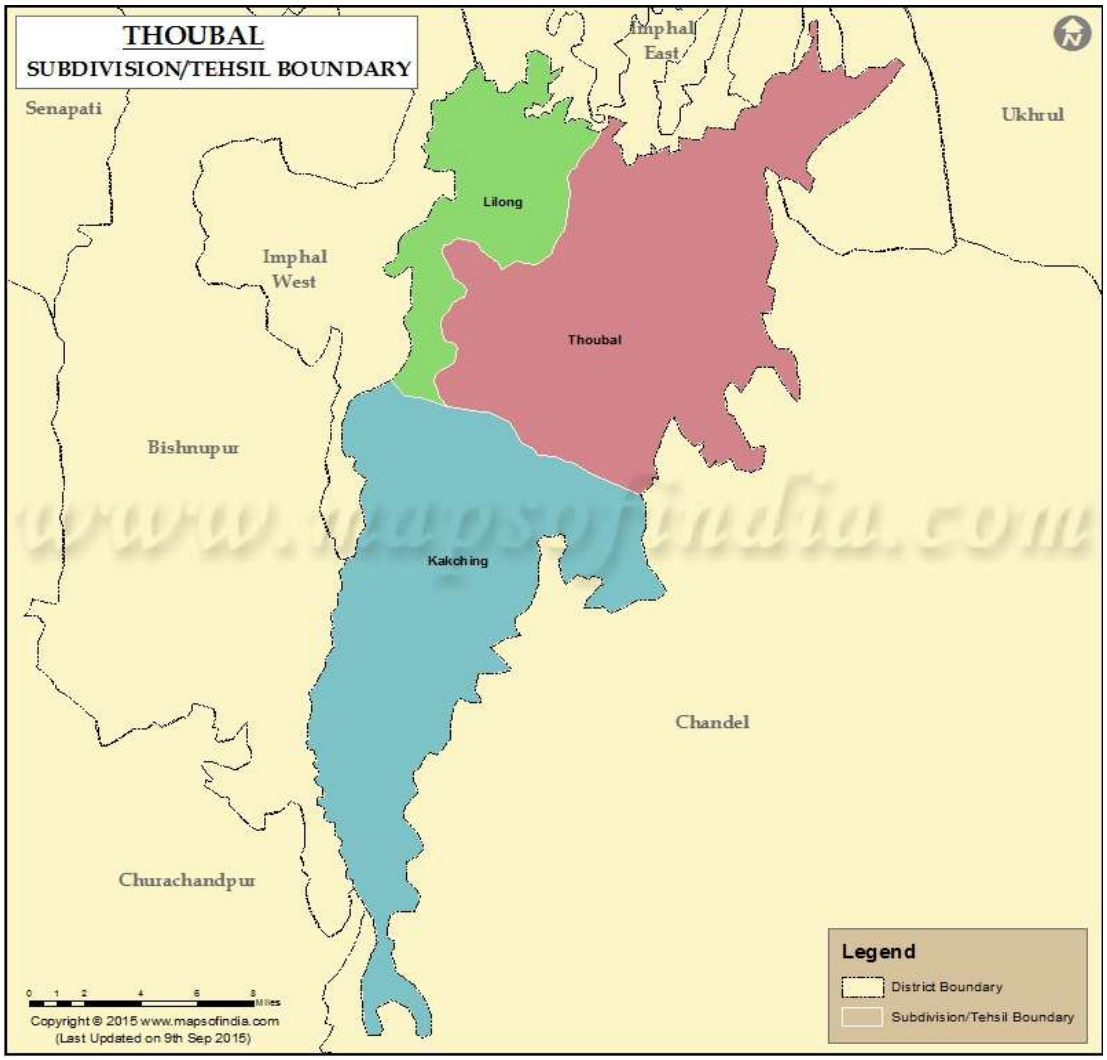
activities of rearing and spinning. The district also has a fair amount of activities in sericulture which generates employment for both males and females (District report, Thoubal, Ministry of Minority affairs, India, 2010).

Table 3.2: Number of health institutions along with bed strength

Category of institutions	Number	Sanctioned bed strength	Actual bed in position
Under the State health department			
State general hospital (Jawaharlal Nehru institute of medical sciences JNIMS)	1	500	76
State TB hospital	1	100	100
State leprosy hospital	1	30	6
District hospital	7	450	295
Sub district hospital	1	50	50
CHC	16	480	344
PHC	85	432	370
PHSC	421	-	-
Allopathic dispensary	20	-	-
AYUSH Dispensary	10	-	-
Under Ministry of Health, Govt. Of India			
Regional Institute of Medical Sciences (RIMS)	1	1074	1074
Private sectors			
Private hospitals and nursing home	26	807	807

Source: www.manipurhealthdirectorate.in accessed on 1st September, 2015

Figure 3.1: Map of the study area: Thoubal district



Source: www.mapofindia.com, Accessed on 18th December 2015

The workforce distribution of the total population in the district shows that 48.70% of the population is in the total workforce, while 51.30% of the total population of the district is non workers. Cultivators comprise the major rural work force. Other workers category which includes services in tertiary sector is the next major work.

3.2.5 Health Infrastructure and manpower of the district

Under the guidelines of National rural health mission, Government of India, District health society Thoubal was established at 2006 August.

Table 3.3: Health care facilities in Thoubal district

Health care facilities	Number
District Hospital	1
Community Health Centres	5
Primary health centres	12
Sub Centres	51

Source: NRHM Office, Thoubal

From the information shared by District health officers to the researcher and study of documents maintained in NRHM office of the study district, it was found that there were 500 village health and nutrition committee in the district headed by Panchayati Raj Institution (PRI) members. Other than the government facilities, home based private clinics are very common feature of health care system in Thoubal. District hospital is 100 bedded and it is newly constructed building and innovated on October 2012. Even though it has proper buildings and spaces, there is lack of facilities, specialist and advanced medical technologies. Therefore, except for minor ailments and stitches, people prefer to go at capital city, Imphal. Following table shows the human resources of the district hospital. Recently, under the Manipur public service commission, around 100 medical officers were appointed, therefore, there are 28 MOs in the district hospital but there is lacking in specialist doctors.

Table 3.4: Manpower in District hospital

Designation	Numbers
Medical Superintendent Senior Gynaecologists	1
Medicine	1
Anaesthetist	1
Pathology	1
MD Biochemistry	1
Paediatric	1
Medical officers (MBBS)	28
Dental surgeon	5
Ayush doctor	2
Ophthalmic assistant	2
Staff nurse	39
Pharmacist	5
Medical store officer	1
Lab. Technician	5
Operation theatre room assistant	2

Source: NRHM office, Thoubal District

Table 3.5: Health personnel (CHC, PHC, SCs under NRHM), Thoubal district

Specialist (Paediatrician)	1
Medical officers	59
AYUSH	14
Homeopathy	6
Dental surgeon	10
GNM	48 (Regular) 24 (contract)
ANM	85 (Regular) 62 (contract)
Lab technicians	6 (Regular) 13 (contract)
Pharmacists	27 (Regular) 16 (contract)
Male health worker	50

Source: NRHM office, Thoubal district

3.2.6 Rational for choosing Thoubal district as study area

Based on the findings of pre-pilot study Thoubal district was chosen as the study area. The district has a registered diabetes patients' organisation 'Diabetes self care society' which was established by diabetes patients. Apart from studying patients and care givers perspectives on diabetes care, study of this patient's network would provide a scope of community involvement in diabetes care and how this network can be a platform for community base management strategy. Other than the district hospital and private clinics which were providing diabetes care services regularly, civil society organisations like International Lions club and local NGOs in this district were actively involved in organising free diabetes camps and awareness campaigns. Therefore, this district gives an opportunity to study different form of services for treatment and care of diabetes such as self care and management by patients groups, Government hospital, private clinics, civil societies, NGOs and the interaction of patients with these available services.

3.3 Pilot study and respondent recruitment strategy

The pilot study was conducted prior to actual study in order to test the feasibility of research methods. The main methodological concern was how to recruit the patients and their care givers. Diabetes self care society, the patient network in the study district had 139 registered member during the time of the study. It was decided to select the patients from this list. After taking permission from the secretary of the network, information regarding members was studied from the records maintained in the network. Discussions were conducted with a key member and 2 patients (registered members) who were actively involved in networks activities. It was found out that most of the members were belong to a particular community-Meitei schedule caste who were settle in Kakching sub division only, one of the three sub divisions in the study area. Members of this network were from only one sub division. Therefore in order to include those patients in other sub divisions and those who were not related with the network, it was decided to recruit patients from the district hospital as well as private clinics in the study area.

The next task was how many of these private clinics were to be included in the study as methodological entry point. There were four private clinics which were giving health care services related to diabetes treatment. They were not specialized diabetes

clinic and provide only Out Patient Department (OPD) services. During the pilot study, informal interaction was done with the physicians and staffs of the private clinics. Permissions were sought from the physician to conduct the study. Out of these four clinics, two are at Kakching sub division. Private clinic 'A' was run by the physician of the 'Diabetes self care society' patients network. So when the researcher approached the clinic, he suggested to interview patients of the network as many of his patients were registered with the network. Another private clinic 'B' did not give the consent to conduct the study. And as the patients from this subdivision were already included in the study through the network, patients from the private clinics from this sub division was not included in the study.

At Thoubal sub division also there were two clinics. One was a diagnostic and x ray centre which functions by employing doctors and specialist from District hospitals and hospital in Capital city, Imphal (private clinic C). As for diabetes, the physician was a medicine specialist working at District hospital, Thoubal. After he finishes his duty at hospital by afternoon around 2 pm, he used to visit this diagnostic centre and treat the patients till evening 6 pm-7 pm for 3 times in a week. Therefore, many of his patients visit him either at district hospital or clinic depending on their free time. When asked the consent to interview the patients coming at this private clinic, the physician asked the researcher to come at district hospital as the study also plan to include patients from both private and government hospital, but gave the permission to come at the private clinic and observe the situation.

Another private clinic 'D' was run by a retired Chief Medical officer along with few other Medical officers of the District who were also working at District hospital and other government health centres. Physicians at this clinic were also actively involved in activities like organising health camps along with different pharmacy and diagnostic centres, organisations like International Lions club and Red cross society. Retired. CMO, the owner of the clinic was also working as resource person for diabetes awareness campaign for school children at Thoubal district organised by an NGO, Rural Development Society under the funding of World Diabetes Foundation Denmark. Diabetes related camps like free screening of blood glucose, complications, retinopathy, and neuropathy were organised regularly at the clinic with the help of NGOs, pharmacy and diagnostic companies. Thus, pilot study of this clinic and its patients gave different dimensions to the present study and an opportunity to gain

insight about diabetes related health care market in addition to patients and physicians perspectives. Therefore based on the above findings and convenience for the researcher to conduct the field work, patients from this private clinic was chosen to recruit patients to be included in the study.

Thus, to recruit the patients for the study district hospital, private clinic 'D' and 'Diabetes self care'-patient network was chosen as methodological entry point.

A tentative interview schedule was prepared and tested during pilot study. The interview schedule, prepared on the basis of review of literature and pre pilot study was translated into Manipuri. It was tested on few patients from the self care society. After this, necessary modifications were made, local terms were included, and final changes were done to make the schedule more understandable and comprehensive.

Next methodological problem was how many patients to be included in the study and how to recruit them.

3.4 Study design

It is a qualitative research design which consists of three sub studies, first is study of patients and care givers on knowledge, perspectives, health seeking behaviours, self care practices and experiences of living with diabetes, second is study of health care providers on their perspectives on diabetes care and services available in the study area, third is study patients network "Diabetes self care society".

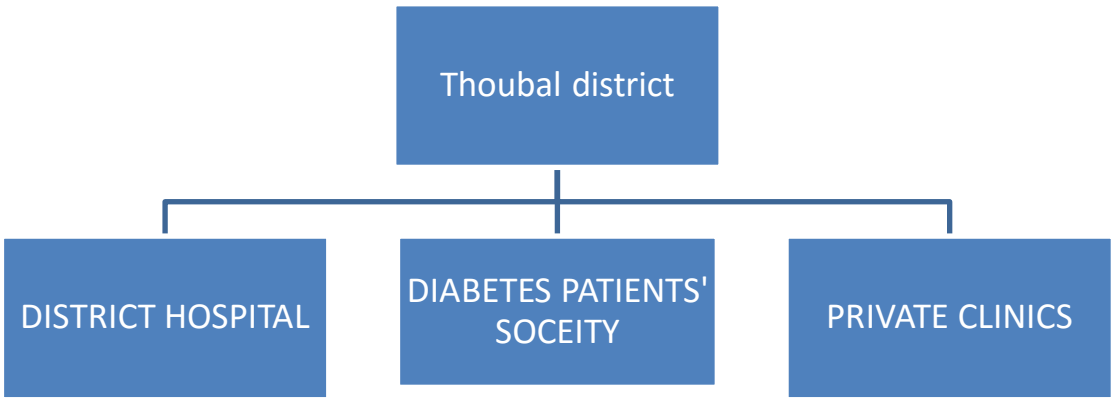
3.4.1 Study of patients and care givers

Sampling strategy and sample size

According to Patton (2002) to ensure that collected information are rich and widely varied, study respondents are selected using purposive sampling and it allows the selection of respondents with different background such as education, employment, duration of illness, different experience with health care services enriching the nature of data collection (Patton, 2002). With this understanding purposive sampling was used to ensure that patients from different health care institutions such as private clinic, district hospital as well as those from the community (Diabetes patients' network) were included in the study as shown in the figure 3.2 below. Aim of this research work is to study diabetes care and management of patients and care givers in

their own social context with different socio economic background such as education status, occupations and income as well as duration of illness. To ensure that study respondents were from different background with different illness experience a base line study was conducted among the patients from these three different sites. Information on socio demographic characteristics and clinical profile were collected.

Figure 3.2: sites for recruiting respondents



Base line study of socio demographic and clinical/treatment profile

Patients from private clinic 'D'

There were 112 diabetes patients in the list of patient maintained in the private clinic. According to the physicians and nurses in the clinic less than 50% follow up regularly. Many of them come only when they do not feel good. Proper home address was not mentioned in the list. Contact numbers of 102 patients were available from the record. They were contacted through phone and some of them were contacted when they visited the clinic for check up. Finally base line information on socio demographic and clinical profile was able to obtain from 100 patients in this private clinic.

Patients from the district hospital

There was no specific diabetes clinic or day in the district hospital. Diabetes patient list was not maintained separately. Diabetes care services were provided as OPD at

general medicine ward. From the pilot study, it was found that there was one physician, specialized in medicine. Diabetes patients usually asked the receptionist for him. However, other medical officers also see diabetes patients. There were 3-4 MOs in the medicine ward and all of them sit together in a room and examine the patients. OPD services were provided from Monday to Friday and timing was from morning 10 am to afternoon 2 pm. Therefore only way to recruit patients from the district hospital was for the researcher to visit the hospital during OPD timing and find out if there was any diabetes patients coming. Therefore patients to be included in the study from the district hospital were to decide when the actual field work was conducted.

Patients network 'Diabetes self care society'

There were 139 registered patients with 84 male and 55 female. With the help of the secretary and other key members of the network details on socio demographic and illness status of the members were collected from the records maintained in the network.

Sample size

Given the nature of this research work it was difficult to decide exact sample size before conducting the study. Goenka, (2002) noted in her doctoral thesis on knowledge and practices on diabetes management that qualitative research contrary to quantitative research does not require large sample size and once field work begin, sample size can be evolve, therefore it is not usually pre specified (Goenka, 2002). Some other literature emphasise that in order to insure a sufficiently wide range of information, 30-60 respondents with maximum variation should be interview (Bernard 2000 as cited in Nguma, 2010). Patton, 2002 suggested, for qualitative research, collection of data should be till data saturation have been achieved (Patton, 2002). According to Elliot and Timulak, 2005, in qualitative research attempts are usually made to 'sample broadly enough and deeply enough' so that included sample can capture all the aspects and variation of phenomena being studied.

A mix of both male and female with different education, employment and economic background, different duration of illness with different sources of treatment, different self care regimens, with or without complications were purposely selected from the findings of base line interview. It was decided to select equal number of patients from

each of three different sites that is patient's network, private clinic and district hospital. Thus a maximum variation sample of 20 patients each was selected from private clinic and patient's network. During the time of study, researcher found out that, in district hospital, on average 2-3 diabetes patients come for treatment and there were many time with no diabetes patient. Usually diabetes patients visit the hospital when it was OPD duty of the senior medicine specialist. Therefore researcher visited the hospital during OPD timing and when this particular doctor was in duty that is three times in a week. Like this researcher had gone there for around one and half month and a total of 18 patients were able to contact for study and most of the patients were from lower socio economic classes with less educated and mostly un employed. The following table show the detail of the sample size and patients recruited from these three different methodological entry points. Thus a total of 54 patients were selected to interview in the final study.

Care givers were selected as convenient, who were available during the home visit to interview patients and who were willing to be part of the study. Thus 14 care givers were interviewed.

Table 3.6: sample size for studying patients

Sites	Total number of patients in patient list	Number of patients in base line interview	Number of patients in final study
Private clinic	112. Out of these, 102 patients were with contact list.	100	20 10 male & 10 female
Patients network	139; 84 male & 55 female	139	20 10 male & 10 female
District hospital	No list of diabetes patient available; decided during the time of study by visiting OPD	18	14 8 male & 6 female
Total number of patients interviewed in the final study : 54			

2.4.2 Study of health care service providers: 2nd sub study

It is necessary to include the dimension of doctors and nurses for in depth understanding of the dynamics of health care. In order to achieved 4th objective that is to study service providers perspectives on diabetes care and management in the district, consultant physicians of Diabetes self care society and International Lions club, NGO, District hospital and private clinics and Service providers of concerned diagnostic clinics and pharmaceutical companies involved in diabetes camps conducted by these organisations were include in the study. Since Manipur is a state with rich culture and traditions with strong believes in traditional healing system. Practitioners of this system were also studied. Total of 18 health care providers and key informants were interviewed as shown below.

Table 3.7: Number of health care providers and key informants interviewed

Consultant physicians	7
Nurses	4
CMO and key health personnel at the state health services	2
Key informants from the NGO and civil society organisations in the study area, who were active in conducting diabetes health camps	3
Traditional medicine practitioner/healer	2

3.4.3 Study of patient network "Diabetes self care society": 3rd sub study

It is case study of Diabetes Self care society in Kakching, Thoubal. Out of 6 Key members, 2 were interviewed (Secretary of the network and Retired Medical officer from the community i.e. Kakching who was one of the founder member as well as consultant doctor of the Network). The reason for interviewing only the secretary and doctor was when researcher approach other key members they shared little information and one of them was local MLA (not possible to interview due to his busy schedule) and asked the researcher to talk with the secretary since he was the person who mostly took the main initiatives of activities and maintained official records in his house.

Focus group discussions were conducted separately for male and female because during the pilot phase of the study both male and female were included in one group but there was lack of active participation from female members in the discussion.

Table 3.8: Details of the focus group discussions to study the patients' network

Particulars	Sex	No of members included in each focus group discussion
Members who were actively participated in networks activities	Male	8
	Female	7
Members who were not actively participated in networks activities	Male	5
	Female	5
Total of 4 Focus group discussions with total of 25 members from the network.		

Thus there were four focus groups. Members were purposely selected to included all the characteristics, longer as well as shorter duration of being a member of the network, different duration of illness ect. Data were also collected from the diabetes patient of the community who were not registered member of the network in order to capture much larger picture. Their contact was gained through the registered members. Thus, 5 diabetes patients were interviewed individually.

Summary table of all the three sub studies and number of respondents interviewed in each sub studies are given in following table no. 3.8

3.5 Study and data collection tools

Data collection was carried out using different qualitative methods such as semi structured interview, in depth interview, key informants interview, focus group discussions, study of records and documents and observation of activities.

Review of literature was done to collect background information on works done previously on Non communicable diseases and specifically about diabetes and conceptualised the study based these reviews. Detail review was done specifically on diabetes-data available, treatment and care, self management practices and barriers in the context of patient's social life. Further study concept was developed from these reviews. After the conceptualisation research questions, objectives and study area were decided based on the findings of pre pilot study. For this purposed relevant health officials were contacted and formal discussions were held. In order to finalise

study design, sample size and interview schedule pilot study was also conducted by interacting and discussing the study purposed with relevant authorities at district hospital, private clinic and patient's network. Documents were collected and observations were done at hospital and clinic as well as activities of the patient network. For testing the interview schedule, pilot interview was conducted among the patients from district hospital, private clinic and Diabetes self care society.

Table 3.9: Summary of all three sub studies and number of respondents

<table>
<tr><td>Sub studies</td><td>Sites of recruitment of patients</td><td>male</td><td>female</td><td>Total =54</td><td colspan="2">Care givers interviewed</td></tr>
<tr><td rowspan="3">Patients and care givers</td><td>Private clinic</td><td>10</td><td>10</td><td>20</td><td colspan="2" rowspan="3">14</td></tr>
<tr><td>Patients network</td><td>10</td><td>10</td><td>20</td></tr>
<tr><td>District hospital</td><td>8</td><td>6</td><td>14</td></tr>
<tr><td rowspan="2">Health care providers</td><td>Key informants (CMO, NGO, Civil society, state health authority)</td><td colspan="3">Physician and nurses</td><td>Traditional healers</td><td>Total</td></tr>
<tr><td>5</td><td colspan="3">11</td><td>2</td><td>18</td></tr>
<tr><td rowspan="2">Patients network</td><td>Key members</td><td colspan="3">FGD (registered members)</td><td>Non registered patients from the community</td><td>Total</td></tr>
<tr><td>2</td><td colspan="3">25 (4 focus groups)</td><td>5</td><td>32</td></tr>
</table>

At first data on socio demographic and clinical history of the participants were collected. With the expectation that participants view point would be more expressive in on open design interview than a standardised interview or a questionnaire, semi structured interview are used in qualitative research (Flick, 2009). It provides maximum flexibility and allows to obtain detail information about the study participants by interacting with them capturing richness of theme emerge from the

responses (Denver, 1995 as cited in Nguma, 2010). It is suggested that questions starting with ‘what’, ‘how’, ‘tell me’ or ‘describe’ should be used as they tend to elicit for personal expression from the participants (Kvale, 1996 as cited in Nguma, 2010). In the present study semi structured interview schedule was used to encourage participants in engaging themselves in the discussion of knowledge, practices, and perceptions on diabetes care, difficulties and barriers in self care. This interview technique was also used to collect data on perspectives of health care provider such as physicians, nurses and traditional healers on diabetes care and management.

The study also aims to generate information on experiences of living with diabetes, their meaning of being a diabetic patient and how these experiences and their perspectives on diabetes influences care practices. In depth interview technique was used to collect this information from the patients and care givers. In this interview technique participant answer to a specific question yet responses can tell individual stories related to the study problem without the influence from others (Flick, 2009; Patton, 2002).

Key informants interview was conducted to collect data on situation of diabetes and health care provisioning on diabetes in the study area. This was done with the state health officials, physicians, key members of civil society organisations and NGOs which were involved in arranging free diabetes health care camps from time to time in the study area. Key informants of patients network “Diabetes self care society” was interview using a check list to collect information on its establishment, activities, funding, benefits to the community and difficulties. For deeper understanding of the ideology and concept behind the establishment of such network and external factors like market influence, in-depth discussions and interviews were conducted with the key members. Focus group discussion was conducted among the registered members of the patient’s network. Observation of activities and study of records were also done as study tool.

3.6 Data collection procedure

3.6.1 Study of patients and care givers

In order to study the patients, the methodological entry point for the field was the district hospital and private clinic which were located at Thoubal subdivision of the District and diabetes self care society at Kakching subdivision. At the district hospital, contact was established with patients by spending time in the waiting areas and engaging in conversations while they were waiting for their appointments. Thus, by building rapport with them, contact number was taken from those who use mobile for fixing appointment and for those who do not have contact number arrangement for home visit was finalised on the day the researcher meet them at clinic and hospital. Their convenient day and time was noted down in the field diary and visited at their home on the specific time and date. For the patients from private clinic and diabetes contacts were already established during the base line interview. Thus the main field work sites were the communities of the patients since the research objective was to explore the social dynamics and relationship of the patient's diabetes care practices in their everyday lives and social condition and to do so from the perspective of the patient. This research methodology was centred on Kleinman's categorisation 'popular sector'. The popular sector means the treatment that takes place outside of the sphere of the biomedical health care system such as patients social surroundings of friends, family, relatives and community. This is where the illness is first encountered, symptoms evaluated and decisions on what to do about it are initiated. The sphere of the biomedical health care system is termed as 'professional sector' by Kleinman and ethno-medicine as the 'folk sector'. As diabetes is a chronic illness, people spend much more time taking care of their illness in the 'popular sector' than in 'professional sector' and 'folk sector'. Therefore, popular sector is considered as the most significant arena of care (kolling et al, 2010; Kleinman, 1988).

As the patients to be interviewed had different schedule due to work variation, some are available at early morning till 8-9 am, some are free at afternoon around 1-2 pm and very least suggested for evening timing because, at evening people go out usually at market and other social gatherings. For office goers, they usually preferred early morning before going to the office. For house wife, after noon was the mostly suggested timing as they were free from house work during this time. It was most

difficult to set an interview schedule with daily wagers like construction workers, women who were engaged in small business of selling and buying vegetables and fishes. Their routine was going out for work early morning around 6 am and come back at home at 11 am for lunch and rest for few hours and again starts the work around 2 pm till evening. So only time available was 11 am -2 pm in which they had to eat lunch and do some house work, rest and get ready for work again. Therefore, they were not able to give enough time for interview. However, researcher tried to collect information with the help of other household members. Since formal introduction was already done and rapport was build, interview at their home was started with normal conversation and requested for consent to use recorder. Care givers who were present during the home visits were also interviewed along with the patients.

3.6.2 Study of health care providers

Approaching physicians at private clinic and diabetes self care society was easier as compare to those at district hospital. At district hospital due to patient load and specific time period, they were always occupied. They usually come at their exact duty time i.e. 10 am and leave right after duty got over i.e. 2pm. Therefore, to interview them, researcher usually sits with them and whenever there was free time in between seeing patients interview was conducted. As 2-3 Medical officers sit together at same room, after collecting their personnel information, some information was collected almost in the form of informal group discussions. Therefore specific time taken for an interview was not able to calculate. At the private clinic, the physicians were interviewed during the afternoon time by taking prior appointment when there was not much patients. Collected information are personnel profile, work experience, general health issues they commonly observed at the hospital, their opinion on diabetes issues in the community, their experience in treatment of diabetes patients, their opinions on self care behaviour, follow up of patients, difficulties in diabetes management as service providers, thoughts on prevention and control of diabetes. Data was hand recorded by noting down on small note pad and transcribed later. Time taken for an interview in the private clinic ranged from 45 minutes -1 hrs.

3.6.3 Study of Diabetes self care society

Since this patient network did not have its own office, visit was made at the house of the secretary. Detail purposed of the research work, how and why the network was chosen to study was explained. After getting the consent, information on patient network and member's profile, available clinical history was collected from the documents maintained in a file. Next, various activities conducted since the establishment of the organisation were reviewed from the reports. The researcher requested for a group discussion with other key members but due the busy schedule of the members and inconvenience regarding the place to gather as they did not have its own building or space group discussion was not able to conduct. Therefore, information gained about the organisation was from the secretary himself and another key member. To record the information, main points were note down in a small note pad. And after the conversation, any missing points were checked using the check list and interview schedule. Thus conversation took 1 hr and 40 mints. Necessary documents were noted down in the note book and some others are capture as images using camera since there was no nearby photo state shop. After the researcher came back at home, all information was transcribed in detail form for the purpose of analysis. To interview the members four focus group discussion were conducted separately for male and female as described above. During the actual study period February 2013 to October 2013, there were 2 health camps and the researcher had the opportunity to attend and observed the activities. Information gained from these activities was included for data analysis.

3.7 Data validation and data triangulation

In this study, at the end of each interview, researcher summarised the content of the interview notes and present to the respondents to check if all the information and issues he/he wish to share were consistent with the researcher's understanding of their responses. They were asked to point out errors or correction or any additional issues to be included in the interview notes. Thus validation of the responses was done immediately after each interview.

Data triangulation means use of different methods, study groups, local or temporal settings and different theoretical perspectives while studying an issue. This is also used as a strategy for improving quality of qualitative research (Flick, 2009, pp. 405;

444). Denzin, 1989 suggested four ways of triangulation such as use of different methods, different types and source of data, use of different theoretical perspectives and involving two or more investigators in the research project with different theoretical background (Denzin, 1989). In this study, different methods of data collection were adopted-semi structured interview, in depth interview, focus group discussions and observations. Collection of data was done from different sub study groups- patients from public hospital, private clinic and community based patient's network, care givers, health care providers both in allopathic system as well as traditional healers and study of patient network. Based on different theoretical perspectives study was conceptualised and data analysis was done.

3.8 Data management and analysis

Before analysing the data collected in qualitative research, they have to be documented and edited. Recording data, editing (transcription) and constructing a 'new' reality in and by the produced text are three main steps in the process of data documentation (Flick, 2009, pp.294)

In the present study multiple methods of recording data was employed such as audio recording, field notes and research diaries. Patients and care givers gave the consent to use voice recorder. Thus details of the interviews and discussions were able to capture. Health care providers, physicians, nurses were reluctant about using voice recorder therefore field notes were prepared immediately or as soon as possible.

Interviews were carried out in Manipuri language, for health personnel and key informant both English and Manipuri were used. Interview data were transcribed in Manipuri and translated to English. According to Strauss, (1987) transcribing data only as much and only as exactly as is necessary to answer the research questions is more reasonable as transcribing data precisely and in detail consumed lots of time which could be use in their interpretation instead. Data collection and analysis were done simultaneously.

To present the experience of people living with diabetes, meaning of being diabetic, how these experiences, perspectives and their understanding influence self care practices and their health seeking behaviour, descriptive and interpretive approach to data analysis was adopted. Literatures on qualitative health research have shown that

different studies have adopted this approach to data analysis. A study on health seeking and health related behaviour for type II diabetes in Tanzania by Nguma (2010) used descriptive and interpretive approach in analysing narratives of the respondents and it was done based on the Miles and Huberman (1994) methods of data analysis. The author reported the finding under each theme with examples of quotes from the respondents which support the themes. Narratives were analysed and interpreted according to what the respondents describes as influencing their health seeking behaviour and health related behaviour for type 2 diabetes. To capture the experiences described by the responses specific verbatim quotes were used. As the current study is similar to this study in Tanzania in its nature, study subject and purpose of the study, the researcher decided to adopt the similar data analysis approach. According to Miles and Huberman (1994) there are three processes in qualitative data analysis: data reduction, data display and drawing of conclusion based on the data. All these are interrelated before, during and after data collection. They emphasised that early data analysis should be done concurrently with data collection which gives time to the researchers to reflect on various issues and meaning of whole work. During this early phase of analysis, the researcher read whole transcribed data set. Understandings and insights emerged from the readings were written down as memos which gave a shape to categorising the data into various themes and sub themes.

Elliot and Timulak (2005) noted that qualitative research often employs a general strategy as backbone for data analysis however it also requires flexibility during analysis. As appropriate, researchers need to develop a working, hands on, tacit knowledge of analysis in what Rapley (2004) called as 'qualitative analysis attitude'. For this present research work, the researcher modified the analysis process as require instead of strictly following the method of Miles and Huberman. In the analysis she tried to find out relationship between themes/sub themes such as causes, influences of one theme/sub theme to another, meaning of a concept/ themes as indicated by previous or later themes and temporal relationship of these themes/sub themes.

After readings each individual interview transcript 'pattern, themes and categories' emerging from the data were noted down (Patton, 2002 as cited in Nguma, 2010). Differences, commonality in perspectives, practices in diabetes care and experiences of living with diabetes were highlighted in the transcribed text and narratives.

Table 3.10: Example of data display table

Questions	Quotes	Repeating Ideas	Rare ideas	Theme	Memo/Notes
What do you think about causes of Diabetes				Knowledge and perceptions on causes of diabetes	Most commonly mentioned causes of diabetes are eating sugar and oily food. Stress and difficulty in home and work environment are mentioned by some. In biological cause importance of insulin and pancreatic function was rarely mentioned. Few respondents believed that contaminated food model and evil spirit, black magic can cause diabetes. Though they gave their responses most of them show some kind of confusion and uncertainty in their reply.
Eating too much sugar and sweets	It is all about sugar, everybody call this diseases as 'sugar disease'	Sugar and sweets			
Eating oily foods	I use refine oil for cooking and try to eat mostly plain and boil food	Intake of oily food			
Stress	Every time I deal with stressful situation in my office, my sugar level would shoot up	Stress and tense environment			

Table 3.10: Example of data display table (Contd.)

Biological reason/hereditary	Doctor said its family thing, my father and uncle are also diabetic.	Hereditary			
Causes are quite confusing	Not sure, it is very complicated	Complicated and confusion			
Consumption of food grown using chemicals	I think we are eating all contaminated foods		Chemicals in fertilizers can cause diabetes		
Black magic/evil spirits	Such things weaken our body and makes it easier to get diabetes		Black magic and evil spirit can complicate diabetes		

Adapted from the data display matrix of Nguma, 2010, pp. 122

Table 3.11: Example of developed themes, sub themes and concepts

Main theme	Theme	Sub them
Care and management of Diabetes among patients, care givers and health care providers	Knowledge and perceptions on diabetes	• Symptoms • Causes • Prevention and treatment • complications
	Treatment seeking behaviour and self care practices	• Multiple utilisation of care • Follow up and non compliance • Self care practices
	Challenges and barriers in diabetes care	• Personnel • Health services related • Difficulties in self care
	Coping with diabetes and impact on life and family	• Coping mechanism • Impact on life and family
	Lived experiences of living with diabetes	
	Health providers perspectives on diabetes care	• Meaning of diabetes • Constraints • Perspectives on better management

Adapted from Nguma, 2010, pp. 123-126

3.9 Informed Consent

Necessary consent was taken from the concerned officials and institutions to conduct the study at the district. Verbal consent from all the respondents in the study prior to the interviews was taken. They were assured that their participation is voluntary and would not interfere with their diabetes treatment in the clinic, that the data would be handled in a confidential manner and their name would not be used in any publication or presentation.

3.10 Presentation of data chapters

Based on the study objectives, data are organised into three finding chapters. The findings are grouped into different themes and sub themes emerge from the analysis process. First finding chapter is about care and management of diabetes among the patients and care givers (chapter 4). In this chapter, finding obtained from semi structured, in depth interview of 54 patients, and 14 care givers are presented under themes and sub themes. Second finding chapter is on diabetes health care provision in the study area and health care providers perspectives. Source of data for this chapter are key informants interview, study of record and documents and in-depth interview of health care providers including physicians, nurses as well as traditional healers. Third data chapter is regarding the patients network 'Diabetes self care society'. Findings from the in depth interview of key members, focus group discussions of registered members, interview of diabetes patients from the same community who were not member of this network, observation of activities are clustered under themes and sub theme and presented in this chapter.

3.11 Analytical frame work

Analytical framework for discussing the findings of the study is derived from various works done earlier on care of chronicity, diabetes and social context. Review works by Raphael et al. (2003) on social determinants of diabetes incidence and management, Brown et al. (2004) on socio economic position on health of diabetes patients provide a frame work on studying diabetes care and management from the angle understanding the factors such as material context of everyday living that shaped personal experience of diabetes, socio-economic status of individual, family, community and over all society. This framework further emphasised the relation of

social determinants with health seeking behaviours, access to care and process of care (proximal mediators/moderators), and distal moderators/mediators such as characteristic of persons with diabetes, their health care providers, their communities, neighbourhood, and health care system (Brown et al. 2004). This frame is used in the present study to analyse over all diabetes management and challenges to successful management.

A concept on 'trajectories of patients' movement' employed by Goenka (2002) on her study on diabetes health seeking behaviours among the practitioners and diabetes patients in Delhi. Four trajectories in patients health seeking behaviour in diabetes care indicated in this study are:

1. Silent phases: this is this trajectory after diagnosis and initiation of treatment patients get lost to follow up which symbolised patients self belief in cure and control nearing cure of his/her diabetes without anti-diabetic medications. Later they come back when complications emerges.
2. Doctor's shopping: this is the phase where patients attempt to obtain better medications and care. They visit more than one doctor or other health care system (allopathic to traditional medicines) after starting the treatment. It is an option in the patients and families ways of seeking better care. Symptoms of hypoglycaemia prompt patients from trajectory 1 to 2.
3. Protective mechanism: Patients who stop, restart, decrease or increase medication on their own is the self protection mechanism which is done without knowledge of health care providers. By self adjusting their medication they might stop visiting health care providers leading to loss to follow up. This progression from trajectory 1 to 2 then to 3 is through knowledge and skill gain from their experiences of living with diabetes or from environmental and social influences of friends, families or TV, news paper.
4. Vicious cycle of hypoglycaemia which patients experience due to stict adherence to medications, diets and other self care practices. As response to warning of hypoglycemia patient responds to it by increasing quantity or frequency of meal, leading to gaining of weight and hyperglycemia in the blood sugar test. On seeing this doctors increase the medication resulting to more hypoglycemia and more hunger. This is th ephase where patinets find most frustating in diabetes managemnt.

Based on understanding of these trajectories health seeking behaviour and non adherence to treatment, loss to follow up and doctor's shopping characteristics of present study is discussed.

Analysis and discussion of present findings attempts to outline the illness stories of the patients, their everyday experiences as diabetes patients. This is analysis is informed by Drummond and Manson's concept of 'age of reason'. This study conducted in Scotland highlighted everday living experience of diabetes patients in thier social context, their priority in ldaily life and their perception influence their decision on adherence to duabetes regime within a structural context. Their decision and course of actions were justified and explained as being benefit to them in that particular time, within his or her concept of benefit. Through the phase of 'age of reason' they highlighted that the rational and logical response patients developed in seeking treatment or practices of self care , their level of complience is influenced by the contexual dynamics where patients live every day (Drummond and Manson, 1990).

This study also draws upon Kleinman's conflicting expliannatory model in chronic care between patinets and provider. Using this model present study discussed and analysed the findings to highlights the barriers and challenges of in diabetes care and management due to different perspectives between care providers and patients. He described that explanatory models are the notions patients, families and practitioners have about a specific illness episodes which are informal descriptions but have significance in treatment of illness. These models are 'responses to urgent life circumstances' and answered questions such as 'what is the nature of this problem? Why has it affected me? What course will it follow? How does it affect my body? What treatment do I desire? What do I fear most about this illness and its treatment?' Thus these expalinations give justifications for their action and they are not static but changes depending on their experiences. This allows patients perspective to be considered in developing treatment strategies for chronic care on the other hand explainatory model of health care providers helps patients and family member in taking decision on their treatment choice. Negotiation between the conflicting ideas might able to remove the barriers to effective care and consider patients psycosocial dimensions and need (Kleinman (1988).

3.11 Summary

This chapter described details on research methodology of the current research work. It is a qualitative study which aims to explore lived experiences of diabetes patients and their perspectives on care and management as well as their care givers and health care providers. After giving the rational for choosing qualitative research method, study setting was described, study area had no specialised diabetes care clinic but services were provided in district hospital and private clinics. Apart from these there were also community based diabetes patients network which provided an opportunity to study this as platform for social support in diabetes care. Deciding respondents, how to recruit them and approach for interview was decided during the pilot study. Source of respondents were private clinic, public hospitals and members of patients network. Total sample size was decided as the study progress. Different data collection tools were uses such as interview using semi structured interview schedule as well as in depth interview, focus group discussion, key informants interviews, observation, and study of records. Qualitative data presentation was done by clustering the findings into theme and sub themes. Lastly how these findings are organised into chapter and analytical framework for discussion of findings was described.

CHAPTER 4

Care and Management of Diabetes among Patients and Care givers

This chapter explores care and management of diabetes among the patients and care givers. Information is generated based on in-depth interview of 54 patients and 14 care givers. The chapter is organised into five sections. First section presents the socio demographic, diseases profile and the clinical history of the patients. Second section discusses knowledge of the patients and care givers. Third section presents health seeking behaviour and self care practices of patients in relation to their social context. Fourth section addresses challenges and barriers in health seeking. Fifth part discusses the impact of diabetes on life of the patients and their family and their coping strategies.

4.1 Socio-demographic and disease profile of the patients

4.1.1 Socio-demographic profile of the patients

A total of 54 diabetes patients were included in the study. They were recruited from different health care institutions: a government hospital and a private clinic. As there was a community based diabetes patients network in the study district, patients from this network 'Diabetes self care society' was studied as shown in the following table.

Table 4.1: Number of patient recruited from different sites

Sites	Number of patients interviewed in the study (Total number 54)
Patients network	20
Private clinic	20
District hospital	14

Out of 54 diabetes patients participated in this study 28 were male and 26 were female. Age ranges of the respondents were 30-45, 45-60 and 60-above. 34 out of 54

respondents belong to Hindu followed by Muslim 15/54. Only 5 of them were Christian. The reason of higher number of patients with Hindu religion is because in the study district majority of population is Hindu with very less number of Christian as presented in the demographic profile of the district in chapter 3. More than half of the study respondents (32/54) were OBC; it includes both Meitei (Hindu) as well as Muslim. It is followed by schedule caste (17/54). Social and caste composition of the study area show that Thoubal district has higher population of Meitei ethnic group who belong to OBC category. Manipuri Muslims (Meitei pangal) comprises another important population group of the district and they also come under OBC category. People belong to schedule caste are also Meitei ethnic group who follow Hindu religion and they are populated at Kakching sub division where Patient's network 'Diabetes self care society' was located. Christian populations belonged to schedule tribe and their number is very less in the study district. Therefore, in this present study there were only 5 respondents who belonged to ST community.

As for the education, employment/occupation status and monthly income number of respondents were nearly equal because they were purposely selected to serve the purpose of the study. Monthly income ranges are lowest 5000 INR to above 40000 INR. Occupation of the patients as reported by them was widely varied. In this analysis, they are group into government employee (which get regular monthly income), self employed including small scale business, shopkeeper, tea stall owner in local markets, daily workers such as building houses, carpentry, tailoring and weaving, private tutors. Another category is house wife and those not doing any work for earning and retired from work.

Further analysis of the socio demographic profile of respondents based on their sites of recruitment that is government district hospital, private clinic and patient's network showed that all the patients (14) seeking care from the district hospital belonged to lower socio economic group with least educated to illiterate with monthly income of less than 10000 INR . They were mostly unemployed, daily wages earner such as selling vegetables in local market or farming in others land without fix income of a day or month. Detail of this background characteristic is given in the annexure no. 3.

4.1.2 Disease profile: clinical and treatment history

Table 4.2 presents the clinical and treatment history of diabetes patients participated in the current study. At the time of developing the proposal for this thesis, the researcher intended to study both type I and II diabetes. However, during the study, no cases of type I diabetes was unable to interview due to health conditions of the patients and shifting of houses. So, in the thesis, diabetes refers to type II diabetes. Findings presented here are as reported by patients themselves and their family member or care givers. Some of the respondents showed their medical record booklets provided by their physician. This information is also included in the findings.

Mean duration of having diabetes was 12 years and it rangers from 1-23 years. They were in different combinations of treatment regimens. Allopathic treatments were use of OHA, insulin or both. Respondents were also taking herbal/traditional medicines along with allopathic treatment. Some respondents were following only herbal/traditional treatment.

Table 4.2: Clinical and treatment history of patients

Type of diabetes	Number of Type I patients: 0
	Number of Type II patients : 54
Duration of illness	Mean duration of illness (years) : 12
	Range (years) : 1-23
Different treatment regiments followed during the time of study	Allopathic treatment: Oral Hypoglycaemic Agents (OHA), Insulin, OHA+ Insulin
	Traditional/herbal medicine only
	Allopathic + traditional/herbal
Complications (Self reported)	Retinopathy
	Neuropathy
	Foot ulcer
	Nephropathy

Information on complications was collected through self reporting of patients as well as cross checking of the medical record that is prescription paper from the hospital or clinic. Complications reported were retinopathy, neuropathy, high BP, foot ulcer. When first inquired about the complications many patients and care givers reported that they do not have any but further probing revealed having experienced blurred vision, tingle feeling at toes. They also had taken treatment for eye and nerves related conditions as well as foot ulcer (diabetic foot). Examination of the prescription/ medical records also showed that they had some complications. Though patients mentioned about symptoms of hypoglycaemia, many of the respondents with diabetes complications were not aware that those symptoms were warning signs of hypoglycaemia.

At first the researcher attempted to analyse the findings and health seeking behaviours of respondents' by categorising them based on their recruitment sites to see if seeking treatment from private care and government care have any influences on diabetes care and management practices of patients and care givers. However during the analysis and interpretation process, it was found that doing so did not add much meaningful characteristic of the findings because many of the respondents were seeking treatment from various sources and health care institutes. For instance, among the 14 patients interviewed from the district hospital only 4 of them were regular attendee and rest of them had sought diabetes treatment from many other health care institutes. Therefore it was not able to establish a link if source of their treatment have any influences on their health seeking behaviours and management of diabetes. Thus findings and analysis are done based on themes emerges from the interview of all respondents generally. However researcher tried to highlights any differences observed among the respondents from different recruitment site.

Next section of the chapter presents the knowledge and perceptions of patients on diabetes type II and its self care and management.

4.2 Knowledge and perceptions on diabetes among the patients and care givers

Knowledge in the context of the study refers to the facts known by the patients or care givers and their experience about diabetes. Perceptions refer to their thinking and view of diabetes and its manifestations within their social context (Nguma, 2010).

In-depth interview was conducted to gain information on knowledge and perception on diabetes care. Their responses are presented in the next section categorising into sub themes, repeated and rare concepts emerged are highlighted. These findings are supported by detail information, quotes and narratives obtained from in-depth interview as shown in table 3.10 (example of data display table) in chapter 3. Knowledge about diabetes among patients and care givers was studied and it was found to be limited. Comprehensive understanding of causes, signs and symptoms, prevention and treatment was lacking.

4.2.1 Signs and symptoms

Question was asked about the signs and symptoms experienced by the patients before diagnosis and if they knew those signs were related with diabetes. Frequent urination (polyuria) was frequently mentioned response. In Manipuri dialect diabetes is called as 'esing pukchatpa' which is translated as frequent urination in english. Therefore, most of the respondents were able to relate this sign with diabetes. Other symptoms and signs mentioned were excessive thirst, hunger, lethargic and tiredness as they said 'always tired'. Weight loss was rarely mentioned.

When respondents were probed on their experience of signs and symptoms before diagnosis most of them were able to described the classical signs and symptoms[1] like sever thirst, frequent urination, excessive hungry, weight loss, tiredness and lethargic and itching around the private part, abnormal vaginal discharge. However it was observed that few of the study respondents had knowledge that these signs and symptoms are related to type II diabetes, more than half of the respondents were not aware about it. Even though they had experienced the classical symptoms of diabetes

[1] Frequent urination, frequent thirst, frequent hunger which are called as polyuria, polydipsia and polyphagia respectively, blurred vision, weight loss, pruritus(itch) vulvae(female), balanitis(men), irritability are the common classical symptoms of diabetes (Watkins 1982).

given the limited knowledge they could not perceived and identified those symptoms as unusual symptoms as in the case of following patient:

> *"Before I was diagnosed, I was always tired; lazy, did not feel like doing anything, sweating and drinking lots of water but never quench the thirst. It was summer time and was so hot. So I thought, may be due to this heat I was feeling like that. But it continued for a long time so I went to a clinic near my house just for check up thinking doctor would give me some vitamins or something but after he asked for blood sugar test, I was diagnosed with diabetes."*

For some other patients these manifestations were associated with a lot of psychological discomfort.

> *"At night I would get up 4-5 times to urinate, so I could not get proper sleep almost every night. Later on I notice some foul smell that comes from the private part; it was itching every time I urinate. I was not able to tell this to my husband. I tried to keep myself clean thinking that it would go away itself but it did not… most of the time I was moody, sad that I did not know what to do with that. I had no idea; this is also one of the symptoms of diabetes".*

And it was observed that those patients who were not knowledgeable about diabetes often confuse signs and symptoms they felt before diagnosis with pre existing health problems. As the following narrative of Mr. L, 43 years old and diabetic for 3 years highlighted,

> *"Before diagnosis, I used to be hungry always, even after I eat properly too I had this feeling that I might faint or fall down anytime. If I work for long my eyes would get blurred. I thought these were because I stopped my BP medicine for some time. I have high BP problem from before and I have been taking the medicine for many years now".*

Opportunistic diagnosed of diabetes and diagnosis as an unexpected episode was a common experience among the respondents. Out of 54 patients interviewed, nearly 80% of them were diagnosed in such way. Some respondents mentioned that they visited hospital for minor surgeries like kidney stone cases. But during the routine check up and investigations conducted the before surgery was performed, it was

found that their blood sugar level was high. Most frequently mentioned terms by respondents which led them in visiting hospitals where they were diagnosed with diabetes were 'loss of appetite, tiredness, always exhaustive and dizziness even after taking proper rest and eating proper meal'.

Knowledge on diabetes and individual characteristics of education status and life experiences: Analysis of responses by categorising respondents into different educational status showed that patients who could relate their signs and symptom experiences with diabetes were mostly higher educated. They reported that they had read and heard about diabetes in newspaper articles and talks by doctors. 2 of the respondents who were illiterate and another 3 who were studied till 6^{th} standard said that though they were not certain but they suspected for diabetes when they visited doctors for consultation because they had experiences of having a diabetes patient in their family and relatives. Patients who had some prior knowledge about diabetes had relatives, family members, colleagues or neighbours suffering from diabetes. Experiences of an individual with a known diabetes patients was an important source of information among this study population.

Mr P. was a lecturer at Manipur University, suffering from diabetes for 4 years and an active member of International lions club. This club held regular meetings and conduct health camps on various diseases in different part of the State. Club members were mostly educated and known people in the society. Many doctors and other health care providers were active members. Mr. P shared that he learnt about signs and symptoms of diabetes from a lecture on diabetes awareness conducted by Lions club. So before he was diagnosed with diabetes, he suspected that those discomforts feeling he had could be due to diabetes. He was diagnosed with diabetes in one of the diabetes check up camp.

This narrative shows how better social position such as higher education status, connection with professionals and exposure to environment where reliable health information can be obtained influences an individual knowledge and perception on diabetes.

4.2.2 Risk factors and causes of type II diabetes

When asked about their opinion and view on causes of diabetes various explanations were given by both patients as well as care givers. Biological explanations of failure of pancreas to produce insulin, non functionality of insulin of the body, eating habits like consumption of oily foods, excessive sugar and sweets intakes, alcohol and smoking, present day system of growing vegetables and rearing fishes or poultries using lots of fertilizers, chemicals, pesticides and insecticides, side effect of drugs taken before for some other illness, overweight and obesity, stress and heredity were mentioned during the interview. Majority of patients and care givers associated causes of diabetes with eating habit, over eating, irregular in timing of lunch, dinner and type of food. They reported higher intake of sugar and sweets as main causes of diabetes (mentioned by all the respondents) followed by high intake of oily food. Though they mentioned that alcohol and smoking should be avoided by a diabetes patient, they did not mentioned these as risk factors.

Eating too much sugar and sweet things cause diabetes:

Diabetes is often described by doctors and health care workers as ‘diseases related with sugar’. Many of the respondents referred to diabetes as ‘sugar disease’. This explains why majority of patients and care givers associated sugar and sweets as causes of diabetes.

> *“Doctors said this is an illness which happen due to too much eating of sweets and sugar”*
>
> *“I have sweet teeth, anything sweet I jump for it. Tea also I used to drink with lots of sugar. I think this is the reason why I have diabetes.”*

Mr. D, 68 years old retired army officer with 19 years of diabetes said he avoided eating sweets as he believed that his diabetes was due to his habit of over eating sweets.

> *“I love all the sweet things and I over eat too. Because of this habit, I am having diabetes. Since I was diagnosed with diabetes, I started to cut down eating sweets slowly and nowadays I even avoid going to community gatherings and rituals invitation I get from my neighbours because they usually serve lots of sweet dishes…if I go, I know I will surely eat and get sick again…”*

Using too much oil in cooking and eating of oily food frequently cause diabetes:

Health care providers often advice patients to cut down intake of oily and fried foods. Therefore respondents felt that high consumption of oily food cause diabetes as one of the patients narrated

> *"Not only cutting down sugar, doctors and nurses always advice us to eat plain and simple food with less oil and salt. Cooking oil also they suggest to use refine oil. Before diagnosis I would eat only fried food with lots of oil and sweets as well. Because of my unhealthy eating habit, I am suffering now".*

Physical inactivity/ sedentary lifestyle/overweight and obesity

It was found that perception on physical inactivity as risk factor for developing diabetes was varied among the respondents with different occupations and their ways of earning income. It was rarely mentioned by house wife and those respondents engaged in everyday manual labour. Obesity and overweight was said as causes by some respondents who their job was mostly sedentary such as working at office.

Mrs. S was 46 years old, having diabetes for 2 and half years shared that her main source of income was stitching bed nets and doing embroidery work which requires her to sit for long time. She said even though she got tired at the end of the day after working with needles and threads, her body weight was always heavy even before she was diagnosed with diabetes. She thought this could be one of the reasons for her diabetes.

Another female patient who was a house wife had to say this

> *"Doctor says when we should be physically active, but the kind of work I do for house, cleaning, maintaining, kitchen gardening, taking care of my child….by the end of the day I can not even move my body….I don't think being sedentary is related to diabetes at least in my case".*

Another respondent shared

> *"I work in farm almost whole day, using all my energy and sweating which is much more than your normal few minutes walks…I don't need to do any*

exercise, causes of this diabetes has to be something else other than being lazy and sedentary."

Stress as cause of diabetes

Stress was one of the factors mentioned by respondents. They relate their stressful experiences at work environment, family, social or financial issues that happened in their life before diagnosis with diabetes as important causes. A respondent, Mr. J was 56 years old, 12 years of diabetes, engineer in public works department said that stressful work environment was one of the reasons of why he had diabetes.

"When I was working for the construction of mini secretariat at our district, work load was so much to handle. I was the in-charge of all the official works. As you know how our state is, there are so many undergrounds militants groups. At that time they would demand money from our department, come at the houses of officers and threatened the families. Along with my colleagues I would go to interior areas hiding from them otherwise they would kill us. Many nights I spent like that. After that incident, my entire health problem started and I was diagnosed with diabetes. I believed this stressful period of life was the main causes of diabetes."

Another female respondent, Mrs. B, 55 years old, having diabetes for 5 years, owner of a small local snack shop in the market had to say this

"My father had diabetes, doctor told me to be care full as I have high chances of having diabetes but for almost 5o years I had lived without diabetes. And suddenly I was diagnosed one day. When I think back it was all to do with what happened in my life at that time. It was a hard time with the death of my husband, earning money to support my children, their education and marriage, taking care of in- laws, repaying family debts…."

These narratives highlight that patient's explanation of his/her illness in relation to their life circumstances and everyday experiences. This linkage of their stressful life experiences and events with diabetes was common phenomena among the respondents of both lower and higher social status.

Biological causes of diabetes:

Biological reason was mentioned by few respondents. When analysed further, these respondents were mostly highly educated and had been suffering from diabetes for longer duration. They shared their interest in learning more about their condition so they read books, newspaper and magazine articles on diabetes; listen to talks on radio and TV.

A male respondent, Mr. G, 64 years old with bachelor degree, a government employee at state education department, living with diabetes for 22 year said

> *"I know about diabetes very well by now, there is no single cause of this diseases, it has lots to do with our food habit, way of life such as stress and biological factors. I have been living with this illness for 22 years now, when I was first diagnosed I did not had much interest in knowing this disease but as time goes by I was not able to get cure and I always had to go to hospital and take medicine. This is when I was curious to know more of this diseases so that I could protect myself, I used to read books on diabetes and talked to my doctors friends, listened to health program in radio. This is how I know about this insulin problem, function of pancrease and how is it affecting our body"*

Respondents also expressed the confusion over the causes. Unclarity about the link between the heredity with diabetes was mentioned by those patients who did not have history of diabetes in the family. Some of them complained that they were neither overweight nor had any one in the family with sugar problem. So, why were they suffering from diabetes as indicated in the following narrative by Mr. A, 51 years old, 8 years of diabetes, manual labourer in housing construction

> *"Doctors said diabetes happen when we over eat foods more than our own body requirement, as it makes lots of fats n sugar in our body system so we need to do exercised regularly for this excess energy to go out of the body…but you see I am a daily worker, I build houses, all the time I am involved in physical activities, when I am not engaged with this work, I go to field, do kitchen gardening. This makes me really tired and exhausted at the end of the day, so I eat lots during lunch and dinner but I am doing more physical activities than doing just some regular exercises. No one in my family*

also has diabetes, I am the first one….sometimes I just wonder, why I am having diabetes."

During the in-depth interviews care givers and patients often brought up questions about why diabetes becomes very common condition in the present day but not before. One of the care givers said

"I heard that diabetes is an illness due to high sugar intake, eating of carbohydrate rich food. In the earlier days of our father and grandfathers, they eat very sweet things like sugarcane juice along with rice, very sweet tea, even the kind of rice available at that time was so different from what we have now. People get rice from their own paddy field, which is very starchy and high carbohydrate contains. But we hardly heard about diabetes during those times. Now it is becoming like a house hold name, at least one of the member in a family is diabetic. I think it is to do with the kind of food we eat now a day. All the vegetables, meat or fish we buy from the market are all contaminated with fertilizers, pesticides, insecticides and other chemicals which are use for artificial growth. This also could be one of the reasons why diabetes becomes very common now."

This reveals how respondents relate diabetes with their environmental context.

4.2.3 Complications of diabetes

Patients and care givers appears to have little knowledge about the complications of diabetes. More than half of the respondents said they do not have any idea about the complications. Among those with some knowledge on complications mentioned about retinopathy, blurred vision, heart diseases, hypertension, kidney failure, foot ulcer, amputation, slow in healing process, nerve problems like numbness, pricking feelings on foot. Problem of eye, vision was most frequently mentioned by the respondents followed by stroke/ BP/ heart diseases , the nerve problems of numbness or pricking feelings on foot or toes (neuropathy) and foot ulcer. Amputation and kidney failure (nephropathy) were rarely mentioned.

Respondents who had some knowledge often answered the question with words like 'I am not sure, there could be or I think' which highlights the uncertainty in their answer. They acknowledged that if they failed to take treatment on time and

medications regularly, the chances of developing these conditions are more as mentioned in the following narrative:

> *"Doctor and nurses told me that it is important to take medicine and check up regularly as this will prevent from heart diseases or eyes problems".*

> *"If we just leave it without doing anything then obviously things will get worse. So we have to get treatment and care"*

In-depth interview of patients and care givers revealed that many of them were having one of these complications but they were not aware about it.

Some of the patients also felt that even if they were regular in treatment and take care of themselves well, these complications are bound to happen sooner or later as highlighted by one care giver.

> *"I know a patient, my friend's father, it has been almost 9-10 years that he has been living with this disease. They are very rich family, they go to good diabetes doctors at Delhi or Guwahati, eat good food, take medicine and check up regularly. His sons or daughters take him out for walk every morning. The kind of care he takes..you should see yourself….but after doing all these his eyes is not good, went for surgery recently, I heard he has a week heart too... I think once you have this devil diseases..all these complications will follow."*

This shows the influence of evidences in the patients surrounding in their perceptions.

Even though many patients and care giver shared their experiences like feeling of giddiness, faint, unconsciousness dizziness, they hardly mentioned about the problem of hypoglycaemia which is one of the major problem of anti-diabetic medicine.

4.2.4 Prevention and treatment of type 2 diabetes

Responses on perception on prevention and treatment goal of diabetes were varied among the respondents based on their understanding on causes of diabetes, cultural belief, and environmental context such as large scale exposure of food items to chemicals.

Most of the respondents were in the opinion that diabetes cannot be prevented. When asked why they think that it cannot be prevented, frequently mentioned reasons were 'as it is related with family history how can we prevent it', 'many of the illness are so much to do with the evil spirit and black magic'.

Since there is a notion among the patients and care givers that diabetes is hereditary and genetically come from the family, they think that it is impossible to prevent it.

> *"If it is already in our body how we can prevent it from happening, it will come out sooner or later. I can't really think how it can be prevented…. "*

The community has a strong belief regarding the forces and influences of evil spirit and black magic in causing disease conditions and whatever happen is all God's wishes. One care giver shared the following thought with the researcher,

> *"Whatever happens, it is all in the hand of God, Human beings cannot do anything against them. Moreover, these things- evil spirit or black magic has very much significant role. My wife has become weak after she encountered this wind which is considered to be evil spirit. After few months she got diabetes."*

Those who were in the opinion that it cannot be prevented have the notion that diabetes is caused by consuming all the artificially grown vegetables, fishes or meats which are contaminated with chemicals, fertilizers ect. This was mentioned by care givers and few patients who had opinion that cause of diabetes is due to changes in environment and consumption of contaminated food items.

> *"Since this illness is related to food we eat, it makes it more difficult to prevent because all the food available now a day are all contaminated with chemicals, artificial flavours or fertilizers. And it is impossible that we avoid eating all these food items? One or another day we all are going to have this disease."*

Due to lack in clear understanding of the causes of the disease, signs and symptoms, respondents also expressed the feeling that nothing can be done as the diseases happen all quickly.

"How would we know diabetes is going to happen? It happens on its own so suddenly, you yourself would not know what is happening to your body unless you feel some serious uncomfortable feelings. That is when you go to doctor and know that you have diabetes. Then only thing to be done is to start the medication…there is really no time to prevent it… "

Opinion on treatment of diabetes was different among the respondents based on their understanding and thinking of what they meant by treatment that is their own concept of treatment. According to their responses, these concepts of treatment can be total cure of the diseases or control of the sugar level in the blood and maintaining it to normal range and preventing from the development of complications.

For those who associated treatment to the concept of total cure, they were very much sure that diabetes cannot be cure. It appears that this belief is more related with the experiences of the patients and care givers than education or occupation. More than half of respondents said the diseases cannot be cure and they have to live the whole their life with diabetes. When probed them with the question of why do they think diabetes cannot be cure, most frequent response was 'have you ever heard of any one cure from this illness?'

"I have been suffering from diabetes for nearly 7-8 years now, if it is curable, I would have been fit and fine by now. Since the time that I knew I have diabetes I was very careful of what I eat, was on medication, regular check up for many years…but see I still have to take these medicines and still have to think twice or thrice before I eat anything."

"I know my relatives, friends and neighbours who are also suffering from diabetes for many years. I have not heard of any of them getting cure. When I go to hospital for check up, I meet all those people with diabetes who I met when I first started to go regularly to this clinic. Nobody says they are cure and stop taking the medicines."

This lack of evidence about getting cure from diabetes was highlighted by patients and care givers as a reason for them to believe that diabetes is not curable.

However those patients and family members who were diabetic for a year and new to diabetes showed the hope that they can be cure if they take care of what they eat and take medications in time.

> *"I was diagnosed with diabetes for more than a year back. Since then I am going to clinic very regularly, taking medicines and avoiding foods which are not good. My doctor said everything will be all right if I take care and I am doing well that my sugar level when I first diagnose was 320 mg/dl in fasting; now it has come down to 120-130 mg/dl. So he said I am controlling the sugar level good enough. I will get cure if I continue to take care like this".*

Few patients were confident that it cannot be cure because main goal of diabetes treatment is not to cure the disease but to control the sugar level to the desirable range. So their concept of treatment is not cure but control from signs and symptoms, control from developing complications.

> *"I have discussed about this with my doctor. He said these medicines are just to keep the sugar in check. We have to adjust the treatment doses according to our sugar level. That's why we need to monitor the sugar level in regular interval. There is no space of completely stopping this medicines…we are going to live with it. So what we are doing is making ourselves relieve from the sufferings of these symptoms, and preventing ourselves from possible complications or delaying the development of these complications."*

> *"See, many people I knew who were diabetic had died after suffering from diabetes for 3-4 years and there are many other people who are still alive with diabetes for 10-15 years not because they are cure from it but they are able to control the sugar level and delayed the complications. So only way to treat diabetes according to my understanding is to control it."*

Those respondents who had some knowledge about the causes of the illness said that it could be prevented even if there is family history. They argued that it is possible to prevent it as diabetes is a disease of high sugar in the body by controlling the eating habit.

"Doctors said it is an illness due to excess of sugar, oil and overweight, then, I think it is possible to prevent it by changing our food intake, doing exercise to reduce weight."

Perception towards the use of insulin as treatment option:

Patients and care givers were reluctant about using insulin. This was shown by most of the patients even among the educated patients. They felt that insulin is the last resort of diabetes treatment. Once one starts using insulin he/she has to depend on it for life and the body will become addicted to it. Participants also reported that they heard other patients using insulin saying 'it is very difficult to maintain, you have to be very particular about the meal timing', 'and it is really inconvenient ', 'painful and it doesn't improve the condition', 'not possible to change the course of treatment from insulin to OHA'.

They felt that if their illness is still at the stage where sugar level can be maintained by OHA, one should not use insulin because body would use to it and it would not be able to response anymore to OHA. Because of these perceptions and beliefs, their attitude towards insulin as diabetes treatment option was not welcoming.

Diabetes treatment is addictive:

Majority of the participants are in opinion that modern/allopathic medicine for diabetes make the body system addicted to it. It has to be taken for long which also leads to various side effects. They felt that herbal medicines are good treatment option which can be taken for longer duration without any side effect as well as they are good for overall body.

Above findings and narratives shared by patients and care givers show that educational status, type of occupation of respondents and care givers, experiences of their own as well as other diabetes patients they knew influenced their understanding and perception about diabetes and its care.

It was observed that respondents and care givers who were more educated and socialised with other educated peoples tried to give logical explanations and reasons for their own perceptions. On the other hand most illiterate respondents replied with

phrases such as ‘doctor said’ ‘nurses in the clinic told me’ or they usually refer to talk they had with other diabetes patients in their locality or relatives or friends.

4.2.5 Opinion on increasing diabetes cases in their community

It was reported by respondents that diabetes is becoming a household name though they were not aware about what is it actually. Sometimes they even compared diabetes with HIV/AIDS which was a common house hold phenomena in the state Manipur decades ago. This thinking and perception of people highlights diabetes as common phenomena in the society. When the question of “have you ever heard about diabetes before diagnosis?” was posed most of them reply with phases like ‘nowadays who does not know about diabetes’ ‘it is very common, everyone is having sugar problem’ ‘you go to hospital, you will find all the complaints are sugar related’ ‘even the tea stall boy know about diabetes, we don’t have to ask them for tea without sugar anymore, they themselves ask if we want with sugar or without sugar. ’

This shows the perceived magnitude of diabetes in the community. They perceived the extent of type II diabetes in the community as a problem which is affecting large number of people. The concerned was expressed by some care givers as narrated in the following quotes.

> *“I think now is the time government should do something about this illness. See, for HIV/AIDS every corner there is NGOs or some organisation working for them. Diabetes is such an expensive illness that I wish there is some free treatment or medical assistance for us too.”*

A care giver, wife of a diabetic patient expressed the need to learn about diabetes for her to be able to help her diabetic husband.

> *There are many people I know who are diabetic in our locality but most of us do not know how to help them except cooking or accompanying them to the hospital. So I feel hospital should arrange some lectures or talks on diabetes for every locality”.*

Those patients who were diagnosed with diabetes long time ago like 20-15 years back said that they did not have any knowledge about existence of such illness. Even after

diagnosis, they did not pay much attention and never thought this could lead to serious complications as highlighted in the following narrative by Mr. N, male, 17 years of diabetes and retired Army officer.

> *"I was diagnosed with diabetes at 1998 when I was in the army. At first I went for check up at our army clinic at the base. The doctor prescribed me vitamins and told me to take rest as it may be due to the heavy duty. It went on for many months and I was losing weight and so restless, then I took leave and came home. I went to RIIMS and doctor told me to do blood sugar test. That is when I heard about diabetes. Before that I had zero knowledge about this illness."*

The above section of the chapter reported about respondent's knowledge and perceptions on diabetes, its signs and symptoms, causes, complications, prevention and treatment, sources of information. They are important factor which determines the treatment seeking behaviour and self care practices. In the following part of the chapter findings of the study on treatment seeking, self care practices are analysed.

4.3 Health seeking behaviour, self care practices and social context of respondents

Management of diabetes, its treatment seeking behaviour and self care practices are influenced by complex interactions of aspects like perception and recognisation of symptoms, its severity, how far the symptoms is affecting the people at emotional, social and economical level. All these factors along with the availability, accessibility and responsiveness of health care providers and institutions influence health seeking behaviour of a population. Adhering to prescribed advices, self care practices are interaction between the individual and social context in which he or she lives. This section deals with treatment seeking and self care practices of the patients.

4.3.1 Places where treatment services utilized

Study findings showed that among the patients included in the study, more than half of them were diagnosed at private clinic. When asked about where they go for seeking treatment during the time of study, most of them responded that they sought treatment from private clinics as compare to government hospitals. Patients also consulted traditional healers as revealed by some of them. This highlights the preference of private hospital and clinics by patients.

4.3.2 Follow up care and monitoring of blood sugar

Regarding the follow up care practices, responses of the patients were whenever there was problem, when the medicines and doses prescribed by the doctor got over, whenever doctors asked them to come for check up. It was observed that newly diagnosed patients were strictly following the self care, treatment practices and follow up once in a month or three months.

4.3.3 Non Adherence to treatment and loss to follow up

Many respondents reported about discontinuing taking medicine in between and changes of health care institutions many times. Following are the reasons mentioned by respondents.

a) Medicines have many side effects if one takes them for long time:

Respondents believed that, having these medicines for a long time will cause various complications in the later part of their life, so they avoid taking medicines every day.

> *"All these medicines are chemical, for some time they will work wonderful for the body but in long run it will affect your heart, kidney. So if the diabetes symptoms are not there anymore we should avoid these medicines."*

> *"Allopathic medicines give temporary relief and make our body used to it which the body cannot give up later."*

b) Inconvenient to buy the medicine

Some of the patients also revealed that they tried to take medicine regularly but sometimes when medicines got over it was inconvenient to buy immediately due to distance of the house from the pharmacy.

Mrs. S is a 46 year old married woman, 2 and half years of diabetes, was a self employed doing embroidery and stitching work at her own home. She lives with her husband and brother in law and she did not have a child. She narrated to the researcher that sometimes she argue with her husband about having babies. She felt depressed, annoyed and powerless so did not feel comfortable to ask her husband for anything she needs.

"…. I do not want to depend on my husband for my medicines every time, so whenever I go to market to buy clothes for stitching work, I used to buy medicines for a month all together. There are times when the medicines got over before I have to go to market. You see…it is such a long distance and time consuming for us to go to market, changing the bus two times. Therefore I just stop taking the medicines for sometimes till the time I go to market. If my husband happens to ask me about the medicine I tell him that it got over and he buys it by himself otherwise I never ask him to buy."

This narrative revealed how the social and family issues in which a patient's living context along with structural issues of distance, non availability of medicine nearby become a barrier and reason for non adherence to treatment.

c) Financial problem

Due to lack of financial resources some patients were not regular in taking medicine. Mr. T, 38 years old who worked as a goldsmith, did not have regular income. His wife was a housewife and lived with three children. He narrated about the financial hardship in his family.

"As much as possible I tried to take medicine regularly but there are times when I do not earn enough in a month and cannot afford to buy medicines. With school going children and not earning regular income it is just so difficult to think about myself and my medicine…."

When such financial hardship comes, patients often prioritised the need of family over their health.

d) Medicines make them weaker, uncomfortable feeling of sweating and dizziness

Patients complained that when having medicine regularly they felt more uncomfortable, uneasy, weak and lethargic. Sometimes they had the feeling that they might fall down, collapse and if they stop taking medicine for some time, they felt better.

Mrs. C was having diabetes for 6 years and she was 45 years old. Her source of income was collecting fresh fishes from the farms which were usually located in the

interior villages and selling them in whole sale price in main fish market at Imphal. She also managed her own small fish shop at the local market.

> *".....hmmm... I m not sure if it is because of the strong medicine or what...Whenever I take these medicines I always get this drowsy and uneasy feeling, perspiring and trembling. I told my son about it and he says it could be due to lack of rest. But even if I take proper rest it happened only. If I eat something I used to feel better. I stopped eating that medicine and I am not going to clinic too."*

During this visit the researcher suggested her to check her blood sugar. A month later the researcher again visited her and she shared that her blood sugar level was low (80 mg/dl). She was having the warning symptoms of hypoglycaemia which made her stop the anti diabetic medicines.

Hypoglycaemia is a major complication of anti diabetic medication. Symptoms are tremors, palpitations, pallor apprehension, nervousness, anxiety, difficulty in thinking, confusion, headaches, dizziness, hunger, poor co ordination, abnormal behaviour, faintness, weakness leading to seizures and coma needing hospitalisation which are signs/symptoms of severe hypoglycaemia.

e) Perceived cure of the illness and perceived ability to control themselves (protective mechanism)

Once started the treatment they felt better and their discomfort symptoms disappeared after taking the medicine for months or a year. So they thought they got cure of diabetes and stop taking medicines until the symptoms again resurface.

A case of Mr. R highlighted 'protective mechanism' of patients adaptation to diabetes management by increasing or decreasing doses of medication according to how they feel. He was suffeering from diabetes for 10 years. He accepted diabetes as part of his life that he has to manage it by his own.

'After living like this for years, now I can feel the changes in level of blood sugar. If I attend any community luch or dinner gathering, I take little higher dose of medicine. Sometime I feel diziness, shivering or extreme hungry as if I would collapse if I dont

eat something immediately. During this time I do not take medication as this shows low sugar level. I have experienced this many times ealier.'

Therefore he did not consult doctors regularly until he was really sick as he felt that he could control blood sugar level himself. This is one of the health seeking behaviour patients developed based on their own rational and experiences in which health care providers often described as 'non adherence'.

f) Unsatisfactory services

Unsatisfactory services such as prescribing many medicines which patients felt unnecessary, not happy with the treatment, no diabetes specialist in the study area were reasons highlighted by patients for loss to follow up.

Thus from the above reasons and narratives it can be interpreted that health seeking behaviour is influenced by patients social status (lack of financial resources), social/ family relations, their perceptions (side effect of allopathic medicines, perceived cure), experiences of living with diabetes (warning signs of hypoglycaemia), structural and health care services factors (non availability of services, pharmacies, unsatisfactory services).

4.3.4. Changes of consultant doctor/ doctor's shopping

Changes in consultant doctors 'doctor's shopping' were quite common as reported by respondents. It was a frequent phenomenon to visit more than one doctor after starting the anti-diabetes medicine. Respondents had developed their own rational explanation for this health seeking behaviour. Various themes emerged from the interview are:

a) Way of seeking better medical treatment and better self care by patients and care givers

According to the patients and their care giver changing doctors is a way of seeking better medical treatment and better self care. Following is the opinion on doctors shopping by Mr. D, 58 years, 9 years of diabetes, working as supervisor in social welfare department Govt. of Manipur.

"....I think nothing is wrong with consulting different doctors. There are 4-5 specialist doctors in our state. I would have consulted at least 3-4 of them over all

these years. Not only in Manipur, I consulted diabetologists at Apollo hospital, Delhi, went for eye check up and other tests at Guwahati. It is just that we want best option for better care and treatment. Medicines prescribed by a doctor might work well to some other but not suitable to other patients. So we need to find out whose medicine is best for our body"

b) Influences from popular sector-friends and families

It was also reported by few patients that they do not have any problem with their consultant doctors but sometime their neighbors, colleagues or relatives would tell about some other doctors whom they sought treatment and find them good and cure from the symptoms. Therefore, according to their influences some patients would go to them.

"I have been consulting two doctors. One is just a medicine doctor at my community, I go to him to discuss simple problems and I also go to Imphal, to see a diabetes specialist. But one of my colleague told me about this particular doctor at Imphal , about his treatment and way of handling patients, advice about self management…I also consulted him for few times." (Mr.Ch. Lecturer, Manipur University, 12 years of diabetes)

c) Experiences and environmental context influencing decisions

Another reason stated by respondents for changing doctor was their unpleasant experiences and unsatisfactory treatment from the particular clinic or physician; they felt that they did not get proper advice or treatment from the physician, not giving them enough time for discussion.

Not only looking for best treatment, patients and care givers responses highlighted that convenient and comfortable environment influences their decision of which doctor to consult and seek treatment. This decision is again influence by the social norms and practices.

Below is a narrative by Mrs. K, 33 years old, female, Muslim and housewife with 3 years of diabetes. Father deceased of diabetes 6 years ago.

"….after I was diagnosed with diabetes, I went to Imphal, RIMS hospital to consult the specialist doctor. During that time, every Thursdays was diabetes

clinic day and I would go there once in a month for almost a year. All kinds of people from every corner come there and such a long queue. When you get your turn, you have…what??Just 4-5 minutes to talk to the doctor. Even after travelling for almost 2 hours, changing buses and auto….that was not really worth at least according to me. Hmmm…not only all these problem..I am woman and a Muslim above that, we are not free to just go by our own like you Meitei women. So, my husband always had to accompany me whenever I go to hospital but he is a driver at police department and had to take leave of absence…everything is so complicated in my family, and three small children, I just can not leave them alone at home...transport cost and treatment cost…later on I heard about this doctor, he is not a diabetes specialist (referring to the private clinic she was attending during the time of study) but his medicine seems to suits me. So I have been consulting him for two years now. I know all the nurses here and they are very kind to me. If I do not have enough money to buy the medicine or insulin, they would tell me to pay them next time when I come for check up. I am very comfortable and satisfy with the services here. It is much nearer to my home, just 20-25 minutes by auto, it saves time and money and I can go there alone, it is such a hassle free."

d) Social status, gender and cultural context

As highlighted in the above narrative of Mrs. K, being a woman above that a Muslim, restrict her from going alone to specialist at Imphal, capital city. The responsibility of taking care of the family, children and husband as a care giver in the society which is again complexes by the structural issues that is distances of the available health services, difficulties in transportation compelled her to change the consultant doctor. It can be further analysed from the above narrative that comfortable environment and satisfaction with the services available are also an influential factor in seeking treatment from a particular clinic and doctor.

For male patients, according to their responses, reason for changing doctors is mostly related with seeking for better care as compare to female who mostly cited inconvenience of distance, need of someone to accompany them. Financial issues like cost of care and transportation was mentioned by both male and female.

e) Perceptions/perceived cure or control of patients

After consulting and having the medicine a doctor prescribed for some time, if the symptoms of hyperglycemia are still persistent, the patients usually go to other doctors.

> *"Before I consulted doctors at district hospital during OPD time for almost 5-6 months but I would not feel anything better, I felt same as before frequent urination, thirsty, lethargic… then I went to consult specialist at Imphal." (Mr. RA, 54 years old, high school teacher, duration of illness 4 years).*

There were also cases that if the patients feel better with the medications of the doctor they consulted first, they stopped seeking treatment for some time thinking that they are normal and cure. When they were not feeling well and symptoms were again resurfaced they would go for medical treatment but from the different doctors.

Mrs. I was diagnosed with diabetes two and half years ago at district hospital, Thoubal. As there was no diabetes specialist in this hospital she consulted one of a known edocrinologist in a private clinic in Imphal. She was on medication and follow up regularly for nearly 6-7 months and she felt much better as put by her husband 'normal'. Therefore she stopped consulting doctors.

> *'She was normal after taking this doctor's medicines so we stop going because it was a lot of tasks going there due to distance and treatmnet was very expensive too, lots of test and diagnosis....'*

Another patient shared

> *"When I was first diagnosed, it was at district hospital by Dr.H. His medicine was good for me. I took them for months and he said my sugar level was control. So I stop taking the medicines for long time. But recently I am not doing well, I feel very weak and lethargic. One of my relative told me about this clinic (private clinic). It is much nearer and opens at early morning so I can go any time before my work start.*

This multiple resort treatment pattern is acceptable in the society. Not only allopathic doctors, patients and care givers also sought treatment from healers and traditional medicine practitioners. Sometimes they seek treatment from both at the same time or

discontinue allopathic medicines. Following section discusses the treatment seeking of diabetes patients and care givers from the traditional medicine practitioners.

4.3.5. Use of herbal medicines/ traditional medicines

Findings from the study showed that along with taking allopathic treatments, patients also sought treatment from traditional healers or herbalist. Of the 54 patients interview 51 said they had tried herbal treatment at least once during the course of illness and some of them even discontinued allopathic treatment and were consulting only traditional healers. Use of such health care services from the traditional healer was in consistent with the tradition and culture of Manipur with widely available of various medicinal herbs and strong belief in healers, spirituality and prayers. Practices of traditional healing as a part of health care services are discussed in detail in chapter 5.

Various forms of traditional healing practices in which respondents have tried were use of herbal medicines prepared by herbalists, including herbs and vegetables which are supposed to be good for diabetes, performing rituals and chanting prayers with the belief that it would chase away evil spirit which they belief to have caused diabetes and taking medicines prepared by practitioners along with prayers.

Respondents expressed their own different belief that herbal medicines cure the illness in a systematic and natural way by treating root cause of the illness. There were distinct polarities among the respondents with regards to use of these herbal medicines. It was reported that for the treatment to be effective, herbal medicines have to be taken during the early course of the illness. Some felt that they should not be taken in combination with allopathic medicines and there were also other section of the respondent who felt that both the type of medicines complements each other so there is no harm in taking simultaneously. Some of them said their symptoms and pain had disappeared when they were using herbal medicines.

Those three respondents who had not tried herbal medicines said they were not sure of these medicines and feared that taking in combination with allopathic medicine might worsen their conditions.

This finding shows that this healing practice has been used by most of the respondents at least once during their illness period irrespective of their educational, occupational

or knowledge status either consulting healer or just tested through friends and relatives. However the way of using these medicines were quite different.

Most of the respondents with higher education and socio economic status reported used of traditional medicine as complementary to allopathic treatment especially herbs which are good for sugar and BP control. Mr L, a school teacher with post graduate qualification was suffering from diabetes for 5 and half year. He shared

> *"I have never consulted a herbalist or healers but I usually include vegetables and herbs which are good for diabetes and other cases like BP in my daily diet. I used to drink the juice of torobot (a locally available vegetable) every morning and in lunch or dinner I tried to eat foods make from banana flowers which is good for body."*

Some respondents completely stopped allopathic medications and took only herbal medicines and they said 'taking doctor's medicine will interfere the healing process of herbal medicines' '*maiba* (Local priest) told me to take his medicine only'. This was mostly expressed by respondents in lower socio economic status. There was no difference in used of herbal treatment among male and female respondents.

Emerging themes from the study on why patients used traditional medicinal practices are unable to get cure of illness by allopathic medicine, influence from family, friends and traditional healers, belief and acceptability by the community and belief about lack of side effects of herbal treatments

a) Not able to get cure by the allopathic medicine

People generally belief and hope in getting cure of their illness very fast after taking the medicine prescribed by doctors. They find it hard to absorb the chronic concept of diabetes. The idea of being careful for whole life with their diet and life style was considered as a major burden by the patient as well as by the family members. Taking medication for long years took a toll on the financial situation of patients and their family. Therefore they often looked for an alternative which is more affordable and belief of ability to cure their illness i.e herbal medicines available at their own community.

"I have been on anti diabetic medication for more than 5 years. When I am taking the medicine I feel fine but once I stop taking them for few months and my blood sugar level went up..... Doctor told me to be on medicine continuously. But it is expensive when you are taking for long moreover it does not cure my illness. Now I am trying this herbal medicine……"

This shows that traditional medicines were used by respondents as response and alternative to failed health care by allopathic medicines.

b) Influences from friends, family members

Interview of patients revealed that, they usually use the herbal medicines through the suggestions of their friends or family members.

"*My friends at office who also have diabetes told me about this herbal tonic...He said this doesn't make him tired unlike while he was when taking only allopathic medicine, so I am also* taking *the same along with the anti diabetic drugs prescribed by the doctor."*

According to them herbal medicines can be taken concurrently along with allopathic medicine so it is easier to use. Patients also reported that they were told that these medicines would cure them from diabetes. As they want to free from their illness they were using the herbal medicines. There were also respondents who said they had never consultant traditional healer personally though they reported trying the medicines or herbs at least once with the recommendation of friends, colleagues or relatives.

c) Influence from the healers and promise to cure

Healers often claimed in newspaper, TV or radio that they have medicines and prayers which can cure diabetes. Some Patients also claimed that they were cured of diabetes after taking those medicines and they expressed their gratitude towards these healers through newspaper. This is a common phenomena in the study community for various other illness not only diabetes. As a respondent shared

"*I saw this advertisement at a local newspaper about this person and seem to be much known among the diabetics and said he can cure diabetes. So I also went….lets see if this helps.*"

d) Community belief, acceptance by the society

Local knowledge and beliefs which are deeply embedded in the culture and society is an important factor in the used of this practice. Faith of people in the healing power of traditional medicinal substances along with mystic belief and spiritual prayers is still very strong.

Following is a narrative by a respondent, husband of a diabetes patient for 2 and half year, he himself sometime prepare herbal medicines as taught by his friends who were traditional healers.

> "*Diabetes is an illness with frequent urination, if you research deeply about our traditional medicine practices by the Maiba/Maibis (Local Priest), you will know that there are some plants which can be useful in controlling frequent urination… they are giving us the medicine based on this knowledge. Therefore, I am now letting my wife stop the allopathic treatment to try this plant medicine which I got from a Maiba I know. Moreover, having lots of Doctor's medicine will cause many side effects later……"*

Findings from this study indicate that influence of community members, family and traditional healers in promoting the use of traditional medicinal substances. Belief of the community in their ancestral knowledge and its power which is closely knitted in the socio-cultural myriad of their society is very strong. This is again complexes by easy accessibility of herbal remedies and the issues of high cost of modern medicine. Even though, doctors and nurses talked about cases of traditional practices and its threat to the life of people with diabetes leading to rapid progression to complications, they still holds a high social status in the community.

This study reported that use pattern of traditional practices by all patients irrespective of social class, education and income status.

4.4. Challenges and barriers in care and management of diabetes

Following recommended self care and management plan and seeking treatment do not come easily for these patients and care givers due to personal difficulties which are rooted in socio economic and environmental context where they are living and other

challenges related to health service provisioning. These challenges and barriers are presented elaborately in this section of the chapter.

According to the respondents, the effective measures for care and management of diabetes are adherence to medicines prescribed by the doctors, regularly going to clinics for check up and monitoring of blood sugar, regular walk, changing eating habits by avoiding foods which are not good for diabetes.

Despite having the idea about measures to care and manage diabetes, difficulties and barriers is there which constrain them from taking care of their health. Based on the analysis of the interview of the respondents, these can be grouped into difficulties related to personnel level such as individual's socio economic characteristics, structural issues of availability, affordability and accessibility of health care services, macro level factors of socio cultural norm of the community, political economy , law & order of the state.

4.4.1. Personnel Barriers: Individual' socio economic position

Personnel barriers: these are the constraints which are specific to patient's efforts in availing services from the clinic regularly. Respondents reported various obstacles which are lack of financial resources, no diabetes clinic in their nearby locality or district, distance factor and lack of adequate transport facility. Problem of availability of time and need of someone to accompany when they go to the clinic was mostly pointed out by female respondents.

Inadequate money to cover the cost of medical consultation fee, for diagnostic purposes, to buy medicines and transportation charges was mentioned as barrier in seeking treatment by respondents in lower income groups and those patients with irregular daily or monthly income. Lack of regular income, unemployment, even among those with regular income and government employee, there was insufficient of money to run the family and they forgo or delayed treatment seeking until the condition become worst.

Following is the narrative of Mr. B with 9 years of diabetes. He had complications of retinopathy, foot ulcers (two toes were already amputed) and neuropathy. He lives with his wife and five children. Source of income of the family was meagre amount of money he got from his pension. His wife sometimes goes for farming in their

neighbour's farm to earn money. To support family expenses and cost for his treatment, the eldest son drop out from college and started working.

> *"I had a small job in the police department. Now I have taken voluntary retirement due to my condition. When I was first diagnosed with diabetes my condition was already worst…that is what doctor told me. Then I started taking insulin and other medicine for 2-3 years and was feeling better. Later, it became very expensive to do the test, go to the hospital, doctor's fee and medicine cost; it was affecting my family and study of my children. I cannot do this to my children, I want them to go to school and be educated. So my health naturally becomes secondary. I stopped going to the hospitals and taking medicine for a long time. Until recently, my vision got blurred; there was something wrong with my foot, then I went to hospital. Doctor scolded me for negligence but what do they know about my condition. See these two toes also got cut by its own. Now doctor is saying that I need to do some surgery for my eyes, all these need money."*

This narrative highlights how health becomes secondary for a patient as they have to take care of the family and education of the children. In such situation they have no option but to stop the treatment. It can be further analysed that due to delaying of treatment the patient had developed various complications which make the treatment more costly and unaffordable. Impact of having a diabetes patient on family and their life is also highlighted by this story.

When the patients could not arrange the money before their appointment date with the doctor, they postponed it till they have money. Mrs. S, a house wife shared how she dealt with insufficient financial issues.

> *"My husband is a teacher in a government school, but his salary is very irregular. Sometimes they don't get salary for 5-6 months. My earning is not regular. I do this, weaving of bed sheets, wrappers and shawls (traditional way) and sell them in the local market. Money I earn depends on how fast I can weave them. So there is no regular source of income in my family. If I don't have money when I am supposed to go for check up in the clinics, I wait for some more time and try to complete the weaving work and I get around Rs*

1000-1500 as profit. This money, I use for my own expenditure on medicine and doctor's fee."

Not only Mrs. S, other respondents who were government employee said that their monthly salary was always irregular. They get salary for 3-4 months all together and they had to save for future months as they were not sure about after how many months they would get salary again. Sometimes half of the money they get would be use in paying off debts. Therefore many times they delayed their treatment or check up until they get salary or could arrange some money. This situation of irregularity in salary among the state government employee was a chronic condition which had been going on for many years in Manipur, leading many families in the cycle of debt.

Not only medical related cost respondents also highlighted that they faced problem with transportation cost. As some patients had complications and serious health problem, it was not easy for them to use public transport to go to clinic. More over they need someone to accompany them. They also mentioned that, diabetes specialist clinics were at Imphal and they had to go early morning without eating anything so that they could do fasting blood sugar test. After the test is done, they would eat lunch outside which is again burden to their financial costs.

Husband of a diabetes patient said

"Every time I have to accompany her to the clinic as she cannot go alone because of her weakness, it is double cost for us, changing the auto two times and paying for lunch…all have to do with money only."

Another care giver highlighted that

"My mother has problem with her vision, it is not possible to take her to hospital using public transport so, I would hired the scooter from my neighbour, put petrol and take her for check up. Not only the money problem for buying patrol, problem is we cannot go to clinic whenever doctors ask if I cannot arrange a vehicle".

When such financial problems are there, family members borrow from the relatives or neighbours or their social networks. If they cannot arrange anything they just forgo their treatment until their condition was serious.

4.4.2. Availability and accessibility of health care services as a challenge in self care

As mentioned in the above section, non availability of diabetes specialists in the study area was highlighted by patients and care givers as a barrier in self care and management. Diabetes care services were catered by general physicians and those who were specialist in medicine and had some diabetes management training. Therefore people go for treatment at Imphal if they want services from the specialist otherwise they had to compromised with the services available in their nearby place.

Distance of the clinics

More than half of the respondents highlighted distance and availability of services as barrier in treatment seeking.

> *"There is no diabetes specialist in our district. So I prefer to go at Imphal. I usually take public transports or my two wheeler. Since it is quite far from my home, I go there at early morning for fasting blood sugar test. Queue is quite long if we do not buy ticket earlier. Then again, eat something and wait for another 2 hours for post prandial (pp test). What makes it more problematic is that doctors refer to those diagnostic centres which they have connection for sugar and other tests. From the doctor's clinic again we have to go to the diagnostic centres. It is very inconvenient to go here and there if we do not have our own vehicle. Result of those tests is available at next day only. So again have to go at next day, get the result and show them to the doctor so that he can start the treatment. So it takes two days to get the treatment. See.. if the clinic is at our nearby place, it would have been much easier. That is why I can not go for regular check up".*

This was narrated by a diabetic patient, an assistant teacher at a private school who had been living with diabetes for 9 years. He further added that

> "*You see getting treatment from the doctor you are comfortable is necessary. I had been going to this particular doctor in Imphal which I feel free to discuss all the problems. If not for this distance I have to drive to go there, I would have visit him regularly"*

Need of someone in the family or a relative to accompany the patient to the clinic was expressed by most patients as well as care givers. This barrier was mostly highlighted by the female patients.

> *"My husband always accompanies me at the clinic since I am not much aware about all these hospital things. More over travelling alone…I can go alone but its feels more secure and comfortable if he is also coming with me."*

Another female patient had to say this

> *"When I was going to Imphal, I always had to wait for my husband's free timing or cousin sister who is also diabetic. We used to go together to the same specialist doctor. Now I started to consult this doctor at nearby my home. It takes me only 15 minutes to go there by public sharing auto. So now I do not have to depend on anyone. Moreover I am satisfied with the service here."*

Thus from the in-depth interviews of the patients and care givers, it could be highlighted that challenges and barriers faced by patients and care givers are complex. These barriers influenced their health seeking behaviours in an interrelated fashion. For instance, barrier in treatment seeking posed by economic position an individual is exacerbated by gender (being female), religions (being a Muslim and female) along with the geographical distribution and availability of health care services.

Long waiting time at the government hospitals and clinics

After managing to be at the hospital, patients and care givers face the challenges of waiting in long queue before the doctors and health care workers come to the hospital. Many of them reported about having to wait for many hours. Patients usually come early in the morning and tried to be in the front of the queue so that they could get the treatment early and go home.

This hindrance was again complexes by the issue of whether the patients could eat something or not before assessing blood sugar. Many of them reported about starving before they get to see the doctors.

Lack of adequate time to consult with doctors and health care providers

Usually two or three doctors would sit in a room during OPD timing at government hospitals. Due to large number of patients, they hardly get enough time to discuss their doubts and ask any questions. It was observed that, after the patients had done the assessment of blood sugar test, doctors would go through the records or old prescription papers of the patients and write the medicines. There was less interaction of doctors-health care providers and patients No proper health or diabetes education was given to the care givers or patients. Meeting with doctor was usually for 5-10 minutes. A patient shared this unsatisfactory care given in government hospital.

> *"It is really frustrating that we would wait for hours and we get less than 10 minutes, we don't really get any time to discuss our problem or clarify our doubts.*

This issue of long waiting time and lack of discussion time was not reported by patients seeking treatment from private clinics.

Non availability of medicines and insulin as barrier in self care

Few mentioned about the non availability of medicines/insulin. It is important to highlight here that those patients who sought treatment from the doctors at Imphal mentioned that sometimes they faced the difficulties of availability of medicines. They could get the medicines easily from Imphal but pharmacies at Thoubal usually did not have these medicines. However this was not a problem for those seeking treatment from the clinics at Thoubal.

Further probing on this issue revealed that the private clinics have their own pharmacies at the premises of the clinic. So doctors usually prescribed those medicines which was available in their pharmacy only. So patients would buy the medicines from there.

> *"If I have money, availability is not an issue. I buy all the medicines from the pharmacy of the clinic I go. Sometimes doctors write the name of medicine which happens to be out of stock in the pharmacy but he would change the name of the medicine to some other which is available in his pharmacy. He said both the medicines are of same composition but made by different*

companies so name is different and there is no problem in taking another medicines."

This was narrated by a patient who is a regular attendee of the private clinic at Thoubal district.

Another patient who goes to this same clinic but irregularly narrated

"Ahh….these doctors write only those medicines which are available in their pharmacies. So compulsorily we have to buy from their shop. We don't get from other pharmacies too and all these medicines prescribed by these doctors in the clinic are expensive too."

"I go to Dr.A at the district hospital or at his private clinic which he opens after he finishes his duty at hospital. Generally I do not have much problem with the availability of medicine; I can buy from most of the pharmacists near the district hospital."

4.4.3 Law & order and political situation of the state as a barrier in health seeking

Economic blockade, curfew, insurgency issues and communal riots are chronic law & order and political situation of Manipur state. Many patients and care giver reported about sudden road blockade or riots in which they were not allow to go out of home. A patient Mr. O told the researcher that due to month long economic blockade in national high way many types of equipment for surgeries and medicines were lacking. During that time he was schedule to have an eye surgery but it got postponed for many months and his eye sights got worsen after that.

4.4.4 Difficulties in self care practices at home

Following doctor's advice on diet, food habit is mentioned by most of respondents as a challenge in self care of diabetes. These challenges are interrelated with the patient's occupation, source of income, financial status and how they live their everyday life.

Mrs C, 45 years old female was diagnosed with diabetes 6 years back and doing small scale business of selling fish. Early morning (5-5.30 am), she usually go to far villages which have fish farms and collect the fishes from the fishermen. Then she

would bring them to the main market using public transport and sell the fishes to other women who have fish shop in their local market. Like this she used to be at market till 10-11 am in the morning. After coming home, she would eat lunch, whatever her daughter prepared before she goes to school. After that she takes rest for a while and does household chores. By early evening again she heads to the market to sell the remaining fishes and come back at home to prepare dinner. In between if she gets hungry she used to eat local snacks available in the market which are mostly sweets and oily.

This is her daily routine she narrated to the researcher when asked about her own self management practice. Then she posed the questioned that "do you really think in such situation I would care to think about the self management of my condition?"

She further continued

> *"My husband is a daily worker, he goes for house construction. We do not have steady income. Both of us need to earn for the ends to meet in the family and for education of the children. I know doctor advise me to be careful of what I eat, to take small meal and frequently and I also know what are good things to be done for diabetes but I cannot really follow all these because of my work and if I cut down all the food intake I get tired the next day and cannot work."*

This narrative shows how the livelihood and kind of life a patient live every day influenced successful self management of diabetes. Even though they have knowledge about diabetes care many of the respondents like Mrs. A could not practice them. This was a common picture among the respondents whose source of income was daily wagers.

Difficulty in dietary adherence as barrier in self management

Many patients and care givers acknowledged dietary adherence as one of the self management strategies in diabetes control. However they highlighted the difficulty in controlling diets. Patients often told the researcher *"controlling what we eat is just so difficult for me because I love to eat. But I am trying."* Since meals are taken along with other members in the family, care givers also expressed the difficulties in preparing food separately for the patient and other family members. Rice is the staple

food in the studied community. It was found that health providers often suggest to patients to eat roti instead of rice. Many of the booklets they give to patients suggest in cutting down rice intake since it has high carbohydrates. However, respondents expressed the difficulty of depending on roti and avoiding rice as it is not in their food culture to eat roti as full meal.

Male, 62 years old and 10 years of diabetes said

> *"Nowadays I eat whatever the children cook, before they used to be very choosy of what they cooked, they also tried to avoid foods which are not good for me. But you cannot stick to this for long. I tried to cut down going to all these social gatherings and cultural programs where there is lunch or dinner."*

Some care givers complained that social and cultural gatherings with lunch are very frequent in the studied community and elders of the family are compulsory to attend. When the elder one is diabetic and attends all these functions and eats oily, heavy meals frequently, it makes the blood sugar level high. If one does not go to all these function, it is considered to be rude as highlighted in the following narrative by one of the care giver

"*As you know, all these cultural and social gatherings, feast happen very frequently in our community. When we get the invitations we cannot just ignore. If we attend those functions and events all the diet control routine get disturb."*

In some families, other family members also follow the same dietary pattern as patient. Homeopathy doctor, 48 years old male, diagnosed with diabetes 6 years ago had to say this

"Yes I am very strict about my diet. I tried to follow the recommended management guidelines taking small meals and frequent snacks. For lunch and dinner my family also eats same as my diet. For example we consumed very less oil and refine one, rice also mixed with the less sticky one we get in the shop, sometimes we take roti, avoid eating fresh fish or other meats frequently. Mostly we eat vegetables. It was hard thing to do but once you start doing it you can follow it easily"

Inadequate and lack of health information as a barrier in self care

Patients were not pleased with the kind of information they get from the health care providers especially about dietary recommendation. Lack of information and confusion over the recommendation make patients and care givers disappointed and this become a hindrance in self care.

"I am really confused about these food things in diabetes. What are good and what are bad? Some say you should eat everything but in less amount..What is this less amount, how do we know this amount or that amount is perfect? See for instance, some say eating white sugar is not good but jeggary is okay. I really don't have clear understanding of this diet management. And we hardly get enough time with our consultant doctor to discuss about it…."

"One doctor would say something and another would say something. You never know what is right or wrong…"

As we can draw upon from the above narratives, inadequate knowledge and awareness about diet management and eating habits is a barrier in self care practices of the patients and care givers.

A care giver, son of a diabetes patient expressed the need of clear and easy to understand diabetes management education by the physicians and health care providers.

"When I first took my father to this diabetes specialist clinic at Imphal, doctor gave me some booklet about how to care and manage diabetes at home. It mentioned about the kind of food a diabetic person should avoid and eat, about exercise and other routine test need to be done. But that section about food talked in accordance with the very India context like eating chapattis and different types of food items which is not eaten in our place. This booklet was developed by some pharmacy companies based in Mumbai. The instructions are not so applicable in our context"

This highlights the importance of culturally and socially acceptable information for diabetes self care. Food and dietary preferences are culturally different from one society to another. It is necessary to consider these cultural factors in giving the health information to the patients and care givers.

One of the spouse of diabetic patients for 12 years said

> *"If you asked further about self care nurses would give you some paper with pictures…all written in English which we can not even read. So what is the point, it just stays in one corner of the house. "*

> *"Doctors said we should eat roti instead of rice because rice has lots of carbohydrates. But we have been living whole our life eating rice as it is our staple food…how can we just change into eating which we never eat before."*

This issue of lack of suitable information on diabetes education was reported by most of the patients in lower socio economic status and less educated.

Patients and care givers often get the advice from the health care providers that a diabetic patient should take small meal and frequently instead of having large portion at one time. Frequent snacks should be taken when they get hungry. During the in-depth interview, patients talked about the financial difficulties of maintaining diets. According to them, now a day various foods are available in pharmacies and shops which are especially made for diabetic patients like sugar free biscuits, fibre contain snacks. However many patients and their families were not able afford the cost of these items as expressed in the following narratives.

"we know about that but we can not even afford to go to clinic for the basic medicine need then how can you even expect me to buy all these…as I said this is the disease to be suffered by rich people"

Difficulties in conducting Physical activities and exercise

Most of the patients had acknowledged physical activity and exercise as an important part of self management strategy in diabetes care. Generally in this community, there is not much concept of exercise as most of the people are indulged in doing some kind of physical activity as house hold chores or as their livelihood. None of the patients included in the study reported doing regular or instructed exercise. However, the norm of going for morning walk had become a common phenomenon among the diabetes patients in the study area. It was observed that as compare to male most of the female patients reported about difficulties in practicing regular exercise.

Only few female patients talked about regular walk as part of their self management. Due to family and house hold chores and responsibility of taking care of their children, they cannot take out time for morning walk. They also felt that since they were always involved in doing all the kitchen gardening work or house hold chores they do need extra physical activities.

Ms. E, 36 years old, 4 years of diabetes narrated

"Doctor told me to go for walk regularly but it is not always possible. I have a 2 years old kid and I cannot just leave her and go. Moreover, as soon as its morning I have lots of work to do so I hardly get time for my own."

Another female respondent shared

"I like going for morning walk, It makes me feel very light and fresh but if I go I have to get up really early so that I would have enough time to do household chores and prepare breakfast, lunch for my in laws, husband and children. Since it is early and stadium is little far, I usually ask my husband to accompany me, he come sometimes but not always. So if he does not come, I also do not go."

"Along with other friends from my locality I go for walk every morning but the problem is we do not have a proper ground or walking path. So we go to main highway. If we go little late, because of all the vehicles, going for walk there is not really comfortable."

From the above narratives it can be interpreted that non availability of enabling environment such as proper track or park for walk along with other social factors of being female, their role as care givers for other family members and need of dependency to other family member often prevent them from self care practices.

Above findings and narratives by patients and care givers revealed various challenges in successful diabetes management which include individual and their everyday life context, structural, socio economic condition specific to a patient as well as over all socio economic condition of the study community, cultural norm and practices, law & orders and political factors act as barrier and challenges. Nature of difficulties patients faced is also differs among respondents from different socio economic status and gender. Though many literature emphasised on lack of understanding and knowledge

as barrier in successful diabetes management, findings of this study show that from the perspective of patients and care givers their social context is the major challenges. It could be interpreted from the above narratives that all these factors do not act individually as barrier but they function together as a complex context in patient's life.

However despite having all these challenges patients and family members develop their own way of living their life with diabetes and coping with it. Findings on this issue are presented below in details.

4.5. Coping with diabetes and its impact on life of the family members

4.5.1 Coping with diabetes

How the patients cope with the illness of diabetes is an important aspect to be considered while studying management of diabetes. Coping with diabetes is a lifelong job.

Family and social support

One of the coping mechanisms was sharing of each other's problems with others who face similar conditions and circumstances, with their family members, close friends or social network. Such interdependence and social support provides an opportunity to share the feelings as well as to gain encouragement.

"I tell my family members wife and sons about my condition whenever I come after seeing doctor. They also talked about people with diabetes whom they know at their work place or friends circles, what they are doing as self care, what food or herbs or supplements they are eating. My family members actually gather the information on diabetes and tell me. We should share, this is how we get support mentally and emotionally."

A care giver whose husband is a diabetes patient for almost 23 years narrated

"If I were not his wife, my husband would have been death by now. When he was first diagnosed I did everything people say about curing diabetes, prepared herbal tonics, consulted faith healers. I attended several diabetes camp organised by different organisations in the state to understand the disease better and even take other ladies

from my community who has diabetic patient in the family. We literally stop eating all the food a diabetic should avoid for his health. Because of financial hardship we even sold our car, TV and refrigerator. Because of all those care at that earlier time, he is doing fine now though small complications and problems occur sometimes".

It was found that patients developed different coping and care strategies by themselves.

Some patients were independently taking care of themselves, adopt the recommended self care strategies, and adjust their diet and insulin dose according to their sugar level. They were closely in touch with health care professionals asking queries about their health. They consider diabetes as a body condition in which they just have to learn to live with. This coping strategy was mostly mentioned by those patients with higher education status, stable source of income and those have been living with diabetes for longer duration.

> *"yes, my wife take care of me by preparing food which are good for my health, I can say she is always in the kitchen but I think it is me who is the sole responsible for my own problem, I keep a track of my sugar level or insulin doses. I buy those diabetes snacks on my way back from office and always keep them with me. Initially controlling the quantity of food intake was hard as I love eating; now I cut down a lot and it is not so difficult*"

> *"I monitor blood sugar myself since I brought the glucometer. This makes the management of diabetes much easier. Now I learn to adjust my meal intake and insulin doses. For example if I attended any social function that means I had much more than my usual so sugar level would be higher, then I take insulin some unit higher than normal."*

There were patients who were consistency in self care practices but relied on others, family members for diet management or health care professionals for self care regimen. They follow the regimens strictly but not much flexibility with changes in the regimen.

> *"I go to clinic regularly, whatever medicine doctor give I take them regularly; I think I am following the advices well. I am very comfortable with my doctor, I trust him"*

"My son and daughter-in-law take care of me. He takes me to the clinic according to the time doctor asked him and his wife does all the cooking. How am I supposed to know all these….I am okay with their care. More over it feels good and assuring to have someone around you."

Coping strategy of some patients was one of denial who perceived that their health is out of their control. Therefore they were not following self care activities. Some of this type of patients revealed that they are aware of importance of self care regimen in diabetes management but they are not motivated enough to follow or compliance to it. Following is some quotes from the stories shared by these patients.

"You know, how hard is it to follow all the recommendation? How much food can you cut down? Every day and night cooking something separately is not just possible. I do not want them (other family members) to be restricted about what they want to eat just because I cannot eat. So I do not really follow a diet plan."

"Every time I think I should go for walk at morning but I always get lazy and I just do not have the enough motivation to do it"

Though proactive coping strategy was mostly adopted by patients in higher socio economic status, these narratives revealed that coping strategy is mostly influenced by motivation of patients to do self care, their skills on diabetes management which have accumulated from long experiences of living with diabetes.

Problem solving and emotional oriented coping strategies

It has been highlighted in the study that men used more of problem solving strategies of coping such as seeking more knowledge about their illness, regular check up of blood sugar, following drug regimen, diet and exercise. Female patients adopted emotional oriented coping strategies such as sharing of illness stories with peer groups and friends.

Spirituality and fatalism

Even though many patients and family members were reacted with the shock reaction, anger and disbeliefs following the news of their first diagnosis with diabetes later on, they come to the term that all are God's plan. Having the faith that everything is going

to work through prayers and offerings to God is also a means of coping among the diabetes patients and care givers.

In the study community, there is strong belief in spirituality and concept of ill health is often associated with witchcrafts or black magic. Therefore family members would go to local priest (maiba/maibi) who considered having power to talk to locally worshiped deities and ask for advice on what to give in offerings and how to clean the bad wind which believed to enter inside the body of the patients. Thus in the healing process, spirituality is culturally essential and relevant coping strategy.

Following is a narrative shared by a care giver

> *"This is something going on since the time of our fore father. For the peaceful life human beings have to offer foods to the local deities which are protecting our village. If we do anything to upset them we suffer through the form of illness. Therefore offering to them and doing fire prayers are important. After my wife was diagnosed with diabetes I went to one of local maiba I know and he did these things for us. I don't know if it really helps or not but we do feel good. This is just a way we follow"*

Coping with stress of diabetes by spending leisure time

Importance of leisure has been highlighted by few patients as their coping mechanism with stress and illness.

> *"It really helps me..Sometimes I just walk by the river, trees and relaxed there, sit quietly. This relives my stress".*

> *"I go out to market with friends and talk to them or watch a movie together, this relaxes me and help in forgetting about my disease."*

A variety of reactions was expressed by the patients when they were first diagnosed with diabetes. There were stage of denial, shock, disbelief, anger, guilt, and depression to adopting various coping strategies by themselves and family members.

Some patient reported that they do not need to let everybody know about their health condition so they shared the information with family and closed friends circle only.

"I don't see any point in telling everyone. I just let my family know about it as they need to take care of me."

For some who do not have much awareness about the disease, the news about diagnosed with diabetes did not have much effect.

Mrs. L, 38 years old, housewife

"I went to hospital to check up for abdominal pain I have been having for quite a time now. After the ultra sound doctor told me that its stone case and I need to go for surgery. Before doing that there was routine whole body check up and found that my blood sugar level was high. So he said I had to bring the sugar level down, only then surgery can be performed. That's why, I am coming to this clinic for diabetes treatment, I have to get cure of it as soon as possible."

Like in the case of above narrative, many patients who were diagnosed newly and did not have much knowledge about diabetes reacted very normally as they believed that this illness could be cure soon after taking medicine for some time.

Denial was common response from the patients when they were first diagnosed as they cannot think about any valid and reasonable causes of their condition. So they often expressed the disbelief state. However, they narrated to the researcher that as they were living with diabetes for long they learn to accept and live with it.

"I clearly remember the first time doctor told me that my blood sugar level was very high. I went to the hospital for some general illness. He suggested me to go for whole body check up. I did that then went to see the same doctor after I get report of the entire test. This is when he said my sugar level was higher than normal. I should go and see a diabetes specialist and do specific test. Still then I was not much worried thinking that something much be wrong. Next day I went to a specialist and I was confirmed with diabetes. I really could not understand why? Because I was not that fat, my work involved lots of movement (house construction worker). I was just 36-37 at that time; no one I know of in the family has diabetes. So in my further consult with doctor I was asking why it is happening with me….I could not really believe for some time. Now…it has been almost 10 years, it becomes part of my life. Once you

are with diabetes means you have to be with it. I learn this now and trying to live well for my kids"

Having the family members or relatives or friends, some of the patients and care givers were not surprised by diagnosis though they reported about being sad and depressed. Many felt the burden in their own life as well as their family members as they knew that it is lifelong condition which needs constant care and money.

"Of course I was so sad and depressed at that time; every time I looked at my kids I could not control my tears because I know what it is like to be a diabetic patient. My father died of diabetes. He was almost 60 when diagnosed and my brothers and sister-in-laws were there to take care of him. But for me, I am just 33 and my kids are so small, except my husband who is there. This really troubles me most of the time. Otherwise I was not shocked or surprised to know that I am sugar patient."

Better coping with diabetes among those patients with strong family support was reported from the study in term of emotional as well as technical support such as helping in diet management, accompanying to clinic.

"I am very thankful to my wife. She is actively involved in taking care of me when I was first diagnosed. Financially also she tries at her best to help the family. There were times that she would go to any diabetes related health talk organised by big hospitals at Imphal. She knows better than me. See my kitchen garden is full of these herbs and plants which are known to be good for sugar control. She and my daughters collected from neighbors. May be that is the reason why I feel that diabetes is not bothering my life much"

4.5.2 Impact on life of family members

The impacts of diabetes on family members are consider as 'hidden burden' and it has been refered as 'family affairs'. From the study of the care givers which includes spouses of the patients, son, daughter and daughter-in-laws, having a diabetes patient in the family is of notable burden and negative impact on emotional and psychological well being, financial condition of the family, high level of distress, negative impact on the work or studies and leisure activities. They described diabetes as burdensome illness which affects everything they do in life.

Sometimes partners of the patients expressed experiencing more diabetes related distress than the patients themselves which was more common among the female partner.

Wife of a patient said

> *"My husband has been suffering from this illness for nearly 7-8 years now. Day by day despite of taking treatment and care, his illness is becoming more problem. His eye sight has become weaker, he is now complaining about ticklish feeling in tips of the toes. Doctor said, it is due to nerve weakness. He is so short temper now. Anything you said he always gets angry. I want to help him but do not know how to…."*

> *"My husband is the only one earning in the family. All the kids are small …still a long way for them to have their own life. What scares me the most is the thought that if anything happen to him, how am I going to live and do for our kids? I am so dependent on him now. Only thing I can do for him is taking care of his diet, cooking and feeding him the food or herbs which are good for diabetes."*

Mr. P, a diabetes patient for 5 years was a chain smoker and alcoholic. After the diagnosis and doctor's advice, he cut down the smoke and alcohol. His son, in 12th standard reported that

> *"Recently my father again starts smoking and drinking. We are poor family, there is not even enough financial sources to take him to hospital regularly..he is now having eye problem, foot ulcer and blood pressure too. My mother is the only one earning now. It is beyond possible for her to take care all of us. So I started, few months back to join a brick farm near my house to help the family at least for food. I am thinking of not going to collage after 12th standard. It would make more sense for me to help my mother in earning money. "*

Some family reported about selling or mortgaging the properties when the financial hardships come.

"We had some saving before and my wife's gold jewelleries. Now all are gone. Few years back she had a serious illness with her kidney which was due to her diabetes. We took her to a big hospital at Guwahati for treatment. Lots of money was spent. We had to take loan from friends and relatives. Till now we are unable to repay those loans."

Another patient said

"We do not have a regular income. I used to go for daily work..that also now I cannot do much because of my health and my wife goes to market for selling vegetables….what can we do..?? I had to do this eye surgery and so many other tests..all are money. We decided to sell part of our land to the neighbour."

Daughter of a patient complained

'Taking care of my mother is impossible task. Sometimes I just stop telling her..I just let her do whatever she wants. Every time I have to remind her to take medicine and not to drink all these sweet tea or eat oily food from the market. But she never bothers to listen to me. How much can I run after her? This really makes me frustrated but again if I go out for long time or hang out with friends, I would be worried about her. You know..My mind is never in peace."

"It is 24 hours job to be with a diabetes patient. It feels like I am also sick…..mentally though physically fine. My father-in-law is a diabetes patient. As you see, he is quite old now, along with this sugar problem he has all the old age illness. Taking care of him is full time job. Most difficult task is feeding him. He wants to eat only those foods which are not good for him. Yesterday I prepared fish curry and since it has lots of oil in the curry I gave him dry fried and he was so angry with me, he said, I was doing that because I don't want to feed him good food. Sometimes I used to think, for how long he is going to live so I better give him whatever he wants to eat. At least he would be happy. If I do that my mother-in-law and my husband would scold me saying I am being lazy and I do not want to prepared food for him separately. Now you imagine, how difficult this could be for me"

Family members felt that it is difficult to manage the disease and the person with the disease as one of the care giver reported

"A diabetes patient can be so short tempered anything you say to them, they can take it seriously and throw tantrum or react in such an inappropriate way that some time you happen to lose control. Living with them is so difficult emotionally and mentally plus financially."

It can be highlighted from the responses of the care givers that they live their life with uncertainty, with the fear that 'what if something bad happen' especially when the diabetes patient is the bread earner and elder of the family. However, despite having all the difficulties in managing and handling a diabetes patient in the family, eventually they all learn to live by integrating diabetes into their everyday life.

4.6 Summary

This chapter presented overall nature of care and management of type II diabetes among the patients and care givers. It attempted to address the issues of knowledge on diabetes care, health seeking behaviours, difficulties and barriers in seeking treatment as well as coping mechanism by patients and family members. Section one of the chapter described the social demographic and clinical profile of the patients. Section two explored the knowledge, understanding and perception of diabetes care and management. Findings showed the inadequate knowledge among the study subjects. Even though majority of them heard about diabetes before diagnosed, they were unsure about causes and symptoms. Certain level of uncertainty was reported by the respondents with regards to preventability, curability or treatability of diabetes. Section three presented health seeking behaviours and self care activities within the social context of patient. Most of the patients sought treatment from the private clinics and doctor's shopping is a common phenomenon in which patients described as their way of looking for better treatment which suits their body. Follow up care and adherence to treatment was low. Most of the patients and care giver stick to taking allopathic or herbal medicines, avoiding sweets and oily foods as their self care practices. Use of traditional medicine and consulting healers or herbalist was in consistent with cultural and social norm of the community which is also influenced by the family members, friends or healers themselves with the promise to cure the illness. Section four examined the difficulties and barriers in seeking treatment. The

challenges faced by the patients and care givers were at personnel level that is lack of financial resources and affordability of medical care as well transportation cost due to distance of the clinic, health services level that is non availability of diabetes care services, lack of adequate time to consult doctors, long queue and waiting time, affordability and availability of OHA and insulin. Apart from this, due to social norms and tradition, female patients highlighted the issue of need of someone to accompany them in hospital if they are going for treatment at capital city Imphal, which is far from their village. Challenges in self care practices at home such as dietary adherence was also reported due to lack of financial resources, social and traditional way of food culture and eating habits. The last section presented the coping mechanism of the patients and family members as well as impact of having diabetes patients in the family. Depending on family or social network for emotional, psychological and technical support was observed from the study. Some of them cope with the illness in the form of spirituality, fatalism, by having leisure time. Impact on the life of family members due to diabetes was notable burden in the form of emotional and psychological well being, financial condition of the family, and high level of distress, negative impact on the work or studies and leisure activities.

CHAPTER 5

Health services provision on diabetes and health provider's perspectives on its care and management

It has been noted that nature of health care system and the way in which health services are provided influences treatment seeking of people in the community. Interaction between health care providers and patients and their relation has been reported as a factor in the patient's decisions to consult a particular doctor and tendencies of people with diabetes to seek care from alternative resources including traditional healers and/or herbalists. This chapter examines the available diabetes care services in the study area as well as perspectives of health care providers in diabetes management and care. First section of the chapter deals with diabetes care provision in the district and second section presents perspectives of health care providers on management of diabetes. These findings are based on interview of key informants from the district and state health personnel, NGOs, civil society organisations, doctors, nurses and traditional healers.

5.1 Provisioning of Diabetes care services in Thoubal district: Study area

Thoubal district has both government and private health care delivery system along with NGOs and civil society organisations providing health camps and awareness campaigns on diabetes care. Government health care system includes sub centres, primary health centres, community health centres and a district hospital (as described in the chapter 3 in details.). In this government health services structure, diabetes care services were available only at the district hospital and there were no care facilities at the village or block level. There were no diabetes specialist doctors or clinics therefore diabetes care services were limited in the study area.

5.1.1. Diabetes care services in government set up: District Hospital

Study of the hospital official documents and interview of CMO, other health care providers: Physicians and nurses showed that there was no diabetes specialist doctor as well as no diabetes unit in the hospital.

5.1.1.1 Service providers in district hospital, Thoubal

Diabetes treatment services were catered during routine OPD timing by medical officers in the general ward and a senior doctor specialised in medicine. Therefore diabetes treatment was given at outpatient facility only. All the diabetes patients who were regularly following up at the district hospital requested to get the treatment from this senior medicine specialist doctor, Dr. X. He had obtained CME trainings on diabetes care and updated his medical knowledge by attending conferences and workshops on new updates of diabetes treatment. None of the staff nurses and other health care workers posted in the general OPD during the time of field work received any specific training on diabetes care though they claimed that they had attended awareness camps on diabetes which was conducted in the hospital one year ago. Health providers reported that they at least have some working knowledge on diabetes management especially about the dietary intakes and exercises.

5.1.1.2 Services available in the district hospital

OPD services were from 10 am to 2 pm. 2-3 doctors usually sat in a room together and attended patients. OPD charge was Rs. 10. Services related to diabetes care available were basic care that is free blood sugar test. Doctors usually wrote prescription on first line of drugs for diabetes treatment and patients had to buy the medicines from pharmacies. If the cases were with complications they referred them to RIMS or JNIM for further diagnosis and treatment as facility available in the district hospital was only basic. Doctors and other health workers told the researcher that once the patient was diagnosed with diabetes, very few of them turn up for the further treatment. They prefer to consult specialists at Imphal. Most of the diabetes patients, researcher met in the OPD visited district hospital to consult for their other illness. Mr. D was accompanying his mother at the OPD and he said

> *"My mother is a diabetes patient; it has been 6 years now. I always took her to DR. R in Imphal. We do not come here for diabetes treatment. Mother got hurt in her hand so we came to stitch the wound".*

Patients who were regularly coming at district hospital for diabetes treatment were patients of the senior medicine specialist doctor, Dr. X as he was the only senior doctor with updated knowledge on diabetes care. During the field work time of this

study, his duty was three times in a week so most of the patients visited only on these days. Other medical officers (general physicians) also provided diabetes treatment services however these diabetes patients were either newly diagnosed on the day or coming for some other illness.

It was observed that there was less interaction between patients and doctors. If the sugar level was high doctors simply told them that they have diabetes so it was necessary to take medicine and take care of what they eat and be physically active. Details on diet plan were not given. No explanation was provided about what is diabetes, what are the causes, possible complications if not treated, self care practices at home and the goal of diabetes treatment.

As observed from the study, diabetes care services in the district hospital was limited to only basic medical treatment (prescribing medications), advices on food habits ans exercises were found to be lacking.

5.1.2 Diabetes care services in private set up: Private clinics

Private health care sector plays a major role in heath service delivery in the district. There were various home based private clinics which were run by individual doctor (specialist as well as non specialist) at their own home. They were mostly medical officers or senior doctors in the government hospitals. Before starting their duty at the district hospital by morning 10-10.30 am, they would treat their own private patients at home from morning around 6 am to 9 am. After their duty is done at the hospital, they either joined other private hospitals or continue their home clinic services. Thus same doctors were involved in both private as well as public health care delivery system. Such system is a very common characteristic among the doctors in the state. Another private health care system was small private clinic usually run by retired senior specialist doctors by hiring 2/3 general physicians and nurses. There were also private diagnostic centre and clinics which hire specialist doctors, technicians and nurses from Imphal to manage the clinic. Different specialist doctors would visit the clinic thrice or four times in a week in a particular timing. The following section discusses about the diabetes care services provided by these available different options of private health care delivery system in the district. This district has three sub divisions (details explained in chapter 3). Private health care services are discussed for each sub division separately.

5.1.2.1 Private clinics at Thoubal Sub division

As in the case of government hospital, there were no private diabetes specialist clinics. Interaction with the senior doctors and CMO as well from the responses of the patients, it was revealed that in the Thoubal sub division there were two private clinics "A" and "B" which provided diabetes care by doctors specialised in Medicine who had received training on diabetes care and management.

I. Clinic A

At the starting the clinic was just an x-ray diagnostic centre and it had been up gradated to a clinic in the year 2008. The clinic belonged to an X-ray technician who worked at the district hospital. It was located at the main market area and around 8 kms away from the district hospital. Facilities available in the clinic were x-ray, ultrasound, ECG, blood sugar test. It had specialist doctors in medicine, gynaecology, orthopaedics, ENT and dermatology. All these doctors work in big private hospitals or in government hospitals at Imphal as well as Thoubal. They worked at this clinic 3-4 times in a week for 4-5 hours in a day. For instances, the gynaecologists was an assistant professor in JNIMS, teaching hospital under the state government. During the time of study, she visited the clinic on Monday, Thursday and Saturday during 1pm to 5-6 pm as these were the timing she had off from her duty at the JNIMS hospital. This was the same case with other doctors too. There were 3 nurses, 2 X ray technicians, 1 ultrasound, 1 ECG and 2 lab technicians.

Diabetes care services were given by Dr. who was the senior medical officer at the district hospital, Thoubal. As mentioned above he was available at this clinic after his duty at district hospital got over. He was from Imphal. So, it was convenient for him to visit the clinic on the same day as he had duty in the district hospital. Here also, only basic primary care facilities were available for diabetes care. Patients who want to get treatment from him usually come to this clinic instead of going to the district hospital OPD. Patients said since they did not have to wait for long they prefer to come to this clinic and there were more time to consult about their illness. For some patient, it was easily accessible as the clinic was open at the evening time, they could visit after their work was done. They also shared that the doctor wrote only necessary medicine. It was observed that though doctor and nurses talk about the necessary of healthy dietary habit and exercise in diabetes management, when it comes to patient

education about self management there was no formal counselling or discussion. Most of the focused was on regular adherence to medication only.

II. Clinic B

This clinic was also located at the main market area of the sub division, just 1 km away from the clinic A. This clinic belonged to a retired Chief Medical Officer of the district, Dr. Y. Before, the clinic was running at his house. In 2007, it was shifted to the present location which was just near the main road and this land belonged to him. At the time of study there were 3 doctors, 4 nurses and 3 laboratory technicians. Dr. Y was a medicine specialist with 35 years of service experience. Another two doctors were general physician working as medical officer at the district hospital. The clinic opened from morning 6-7 am to evening 5 pm. Services were only outpatient and it had ultrasound, X ray, ECG facilities. The clinic also had its own pharmacy. There were large spaces and halls in the building of the clinic which were usually rented out to NGOs and other community organisations for their monthly meetings and other activities. For instance, health camps, awareness programs organised by Red Cross society and International lions club were conducted at this building. Owner of the clinic, Dr. Y as well as other doctors and staff members were all actively involved as life members or office bearer in both lions club and Red Cross society. Consultancy charge was Rs. 150.

Diabetes care services were provided by Dr. Y as well as other two doctors, though most of the patients ask for Dr. Y as he was the senior doctor. He was not a diabetes specialist though he had attended trainings on diabetes treatment and management. There were no specific diagnostic facilities related with diabetes complications like HbA1C test, kidney function test, eye check up or lipid profile test in the clinic. Charge for blood sugar test was Rs. 60 and for Post Prandial test (PP), nurses provided glucose with a glass of water in which the charge was Rs. 10 extra.

Diabetes patients came for treatment at early morning around 7 am as they need to do fasting blood sugar test. It was observed that patients who were regular and had been coming to the clinic for a long time were in a close relationship with the nurses and other health care providers. They often shared their illness stories, family problems and financial difficulties. If they did not have enough money to buy the medicines

during their visit at the clinic, they were asked to take the medicines and give the money when they come next time.

It was reported by the health providers in the clinic that diabetes care related free camps were conducted frequently in the clinic in associations with these organisations- Red Cross and Lions club and other pharmaceutical companies. Dr. Y along with those patients who were regularly following up diabetes care in his clinic tried to establish an organisation of diabetes patients only. When the patients came for treatment they were informed about this organisation and told them this would help them in keeping contact with other fellow patients. Thus it had a list of 112 diabetes patients updated till 2013 February. This was first started at 2010. When they first joined the organisation, they were provided with an Identity card and booklet for their medical record. However, not all the patients coming for diabetes treatment were not included in the list. Some patients refused to be part of it and out of these 112 patients less than half were regular in following up their treatment.

The concept of introducing such patient organisation as shared by Dr. Y was 'for the collective benefit of the patient'. Various pharmaceutical companies who came to sell their products in his clinic offered him to conduct free sugar test and other test to identify various diabetes complications. So he thought why not use such opportunity for his patients. Therefore he shared this idea with those senior and educated patients in his clinic and they agreed to have such an organisation. When such camps happened, nurses and regular clinic attendee patients contacted other diabetes patients through phones and asked them to come for the camps. Patients other than in the lists were also participated in the camps.

Interviews were conducted with the doctors, nurses, patients of this clinic regarding the heath camps and other diabetes care services in the clinic. Dr. Y shared with the researcher

"In last 4-5 years number of diabetes patients coming for the treatment in my clinic has increased. All these pharmacies companies are offering to conduct health camps and free sugar test. So I talked to few of my patients whom I have been treating for a long time about this opportunity and ask if they would like to form an organisation where all the patients can be together. This is how we started this patient's group."

Interview with one member said

"When it was first started in 2010, we tried our best to collect people when the camps happened. I used to call almost everyone's phone number in the list and informed them. Their responses were quite mix. Some responded very happily that there are people concerns about them, some acted in a way that they do not like people talking about their health. It was a hard thing to do because members were from different places and communities, we did not have any formal meeting except during those camps so there was no real bonding or understanding among us. I think because of this we were not able to maintained the organisation. Now it is not functioning at all. "

The organisation was active for only few months. And there were no activities going on except informing them during the camps. When probing the Dr. Y about it he said

"People are not active; they do not want to get involved directly. They are already stressed with having diabetes. So, they do not feel comfortable advertising about their condition in the public. Since such organisations do not get any support from other sources, patients themselves have to make it work but they were not motivated enough to do so. I was helping them in the way I could by arranging all these free health camps."

Interaction with the patients during such camps revealed different dimensions of the story. There were few patients who said they were happy about these services and some other was critical about the real benefit of such camps as narrated by a patient.

"Yes, it is a good thing that we are getting this opportunity but the real challenge is what happens after they diagnosed us with those problems. This time there was a free camp on checking nerves strength and nurses informed us that we should get it check as nerves become weak when we have diabetes. After the test was done they give a report card and asked to meet Dr. Y, he said I should take some vitamins and injection to make the strength of my nerves. He wrote many other medicines all of which I had to buy myself above those diabetes medicine. I just felt it was unnecessary; I was doing fine even before I knew about the weakness of nerve, now also I am doing the same as before even after I took all those medicine and injections. It is like if you go to doctor whether you are sick or not, you always come back with

some sickness and medicine. So when they are not helping us with the further treatment what is the point of doing these camps? It is more like they were trying to sell their medicines. "

Another patient narrated his experiences

"I have been living with diabetes for 6 years now. I consulted different doctors over these years. My neighbour who was a regular patient of this clinic informed me about a free eye check up camp. So I went as I was having problem with seeing things. Doctor said my eyes are affected because of diabetes. I should consider surgery for putting eye lens. Then, they gave me a date and made further arrangement for free surgery at Shija Hospital (a private hospital in Imphal). They said I do not have to pay for anything, all the cost will be bear by the camp organiser. They even made arrangement for transportation. At Shija hospital, they gave me some choices about the quality of the lens. They said if I want to use the better lens than the one they were giving us for free, I had to pay extra Rs. 3000. Those people who could afford paid extra for that better quality lens. People were saying with the cheaper lens eyes would get bad but what I can do...that was huge money for me. So I had to settle with the free lens. Later on whenever we go for check up we had to pay all the expenses and this is a big private hospital, just for OPD consultancy they charged Rs 500. This expenses along with medicine and transportation cost for a visit to the hospital I had to spend more than Rs 1000. There is nothing actually free here"

This free eye check up camp the patient narrated was conducted by District blindness control society with the help of Shija hospital, Imphal, one of top private hospitals in the state. Camp was done at the campus of the clinic B. This was how most of the diabetes patient of this clinic attended the eye check up camp.

Patients were disappointed with the kind of services they received from the free camps. One patient said

"I do not have much problem with my diabetes now. Recently, there was a health camp and my younger sister in law who is also a diabetes patient asked me to go with her. So we went. But there was nothing much. I thought they would give us free medicine and blood sugar test"

Ms. L was a school teacher and her husband was suffering from diabetes for 4 years. Most of the time she accompanied him at the clinic for routine check up and tried to learned about diabetes, how to help her husband in its management and self care. She expressed her opinion on such health camps to the researcher.

"Most of the time I accompany my husband in health camps and clinics. I think not only giving us the treatment and medication they also should tell us about how to care and manage diabetes patients in a family. There are many things I don't know about diabetes, it is so confusing what to cook for lunch and dinner so that my husband also could eat. Doctors always talk about adjusting the dose of the medicine and insulin according to the sugar level but I do not actually understand all these things clearly. Even if I want to help him...sometimes I find myself so useless. Giving a public talk on all these issues would be good."

This narrative highlights the need of clear knowledge and understanding of diabetes among the patients and care givers. So instead of focusing only on the treatment part, integrating awareness campaign and diabetes care education in such health camps may serve the wider needs and interest of the people. As we can see from the above narratives on the activities of these camps and the clinic as well as observation by the researcher, treatment with medication was given more importance in diabetes care services while ignoring the preventive aspects like health promotion, healthy living as important aspect of diabetes management.

5.1.2.2 Diabetes care services at Kakching subdivision

At Kakching subdivision, there were few private clinics run by individual doctor either at their home or at a rented building in the market area. As informed by the patients and other health care providers most of the services were basic care with facilities only for testing sugar level. Services were provided by non specialist doctors. Among these clinics there was one clinic which was run by a senior medicine Doctor, Dr. Z, Retired Medical officer. He was also the consultant doctor of the diabetes patient's network 'Diabetes self care society' in this sub division. He told the researcher he did not have any regular diabetes patients. They were diabetic but came to his clinic for some other common illness. Most of the patients prefer to go to Imphal to consult with diabetes specialist. Whenever patient's network had monthly gathering he tried to be there with the community, talk about diabetes and discussed

their queries. Dr. Z contacted pharmaceutical companies and diagnostic clinics at Imphal and help in organising health camps with this patient's network. Detail about this patient network is discussed in next chapter.

Community members and health providers informed that most of the people in this block area (Kakching) first consult at small private clinics in their locality then would go to Imphal for further consultation. They responded there was not much specialised care in the district hospital. Whatever services available in district hospital were also available in the private clinics and hospital of their sub division. So, they prefer to go direct to Imphal instead of stopping by at district hospital.

5.1.2.3 Subdivision-Lilong

This sub division is at the border with capital city Imphal. It was more convenient for the people there to go to Imphal then come down to the District hospital in Thoubal sub division. So for minor cases only they consult the private home based clinics. As for diabetes care most of the patients go to specialist at Imphal.

In all the private clinics as well as in the district hospital, records of patients were not maintained properly. They used patient held, paper based medical records such as small booklet in which patients carried with them during visits to clinics. Detail information on investigations, medications was recorded in this booklet by the doctors during each visit of the patients. For the purposed of follow up visits patients were supposed to bring the booklet. In the private clinics there were no detail medical records of the patients. However in the district hospital, records of patients coming to the OPD were entered in a registered and this record was used to make a report on number of patients with particular disease. As described above, only few patients come for diabetes treatment in the OPD and many others who were diabetic came for other illness. So in the OPD register, medical records of such patients were not entered as diabetes but other illness in which they came for treatment. This probably led to under reporting of number of diabetes patients.

This study shows the non availability of proper diabetes care services in case of treatment as well as knowledge on self management and care. This was highlighted in the chapter 4 and it is one of the factors that determine the health seeking behaviour of the patients.

5.1.3 World Diabetes Foundation-Local NGO partner project on Diabetes prevention and care (Project No. WDF-12-739), 2013-2015

Rural Development Society (RDS) is an NGO located at Wangjing, Thoubal District. In partnership with World Diabetes Foundation, RDS was implementing a project on Diabetes awareness and prevention among the school children in the study area during field work time. Information provided below about these activities was obtained from official records, interview of key personnel as well as observation of their activities.

The goal of the project was to prevent obesity and diabetes among the school children and adolescents through awareness and lifestyle changes. Program was being implemented in all the three sub divisions of the district including rural, semi-urban and urban areas over three years, 2013-2015. Both government and private schools from different localities were selected and 'one day training camp' were held. During those camps not only students, teachers, parents and other people from the locality also attained the camps. Usually the NGO invited diabetes specialist to deliver lectures on diabetes, obesity, importance of health eating habits and exercises. Participants were given chances to ask questions and clear their doubts after the lecture. After this session, free sugar test was conducted by health care workers.

On the 14th of November, the NGO observed World Diabetes day along with these schools. Essay competitions, quiz, road shows, rally were also conducted to spread the news about diabetes. Publishing a newsletter on world diabetes day on local language was also in the project approach.

At the end of the project, it was expected for RDS (project-partner) to lobby with the state government to include perspectives on diabetes care in state health care services.

The researcher had the opportunity to participate in one day training camps held at schools as well as life style modification training of parents and teachers during the field visits. Lecture session was happened after lunch hours, students were informed about the program 3-4 days before it happened and ask them to spread the news to their neighbours and family. Thus trainings were attended by parents, teachers, students and other interested community members.

Dr. Y of the clinic B, a private hospital at Thoubal subdivision, former CMO of the studied district was the main resource person. He delivered lectures on basic

understanding of diabetes, its symptoms and causes, how we can prevent them, its management and care-dietary habit/physical activities After the lecture, there was questions and answer sessions, Mostly parents and teachers asked their queries and many of them were already diabetes patients. They were happy to get such opportunity to talk about diabetes with the health professionals. However from the observation by the researcher, most of the discussion focussed on the care and treatment of diabetes rather than telling the student way of preventive from diabetes by adopting healthy way of living such as regular physical activities, eating healthy foods.

Random blood sugar test was done and those at risk were suggested to for fasting blood sugar test and PP. Difficulties in project implementation was shared by NGO key person. Project co coordinator of the RDS shared with the researcher that lack of qualified resource person, doctors as well as health care workers, nurses was a difficulty and barrier in successful implementation of the project.

He shared:

> *"We tried calling experts from Imphal but they did not agree to come as the place where we are conducting the camps and trainings are far. Lecture sessions happened for only 2-3 hours. We have to pick them up and drop them back. These journeys take more time than the lecture session so nobody was willing to come. We had to compromise with whatever the resources we have. Developing IEC materials in suitable local setting and language is also quite a difficult task. We have to go and meet all these specialist doctors and request them for their help, all the information need to be accurate....it is such a tedious job to do in a resource scarcity setting like ours."*

In spite of all these, the project was successfully operated by spreading news and awareness about diabetes.

5.1.4 Diabetes health camps organised by community based organisations and care services provided by traditional healers

Along with the services provided by the hospitals and private clinics, activities like awareness campaigns, health camps arranged by Diabetes patients Society, and other civil society organisations like Lions club added to the diabetes care services available

in the study area though they were not continuous services and conducted only some times.

Consulting traditional healers were common practices in seeking health care for diabetes. Nurses and physicians agreed that their patients had visited or sought treatments from any traditional healers. Other key informants also acknowledged that they are important part of people in the state when it comes to seeking health advices and treatment. Healers performed their practices in different forms such as using only herbs, plants and roots or combination of these natural products along with spiritual processes like doing prayers. Some healers claimed that their knowledge on health care and making herbal medicines were inherited from their fore fathers and some other said that they were prophesised by local deities and told them about secrets of these medicinal plants and process to check on human system. Such practices were both in commercial way as well as only locally available services.

There were often advertisements in local newspapers and cable TV channel about such traditional healers. They claimed that their herbal medicines and ritual practices of conducting prayers can cure many diseases including diabetes. Apart from self advertisements, family and those people who already sought treatment often expressed gratitude to the healers in a section of local newspaper that they were cured completely by their medicine and treatment processes. They are called as Maiba (for male) and Maibi (for female). Many of them also practiced locally that is only the local people who know them visit privately with the request of making herbal medicine/tonics. Not specifically for diabetes but generally for everyday ailments in the study area, ill health is associated with evil spirits and black magic. Therefore along with allopathic treatment, people do rituals and prayers in consultation with these indigenous healers. This is common phenomena when it comes to long term chronic diseases like diabetes. Other traditional medicine system of India, AYUSH were not common though there were few small private clinics and AYUSH doctors in the district hospital.

Thus, in the study area, diabetes care was provided in various forms of service provisions such as government hospital, private clinics, NGOs, community based organisations, patients network. Traditional healers which were specific to the study community were unique diabetes care services in the area. It was also revealed from

the study that there was lack of proper diabetes care services, especially for the system of continuous care which is necessary for chronic care; services were limited to basic treatment with no diagnostic facilities to indentify complications. Whatever the inadequate services available were focus to treatment and curative part only and provided by private clinics. As from the study of the district hospital, we could say that there was no attention from the state health services on diabetes care. Most of the health camps on diabetes were conducted by private pharmacies and diagnostics companies in association with private clinics. All the referral systems for complicated cases were channel through these private set up. Thus, in this study area, diabetes care services were given mostly by private health care sector.

5.2 Health care providers' perspectives on Diabetes care and management

4.2.1 Characteristics of Health care providers and practices

In-depth interviews were conducted with seven doctors, four nurses, two traditional healers, Chief Medical officer of the district, one key informant from state health services and three key informants from NGO and civil society organisation to study their perspectives on diabetes care. Characteristics of health care providers are shown in the following table 5.1.

Total of 18 care providers were interviewed comprising 9 female and 9 male. Age range was varied from 30 to 65 years, with practice years ranged from minimum 2 years to 35 years of experiences. Details on their qualifications, service location like government hospital or private clinics is presented in the next table. As display in the table, many of the health care providers were working at more than one health care institutes. For instance, three specialist physicians (MD medicine) were interviewed and one of the specialists interviewed was working as senior medical officer in the District hospital as well as consultant physician in a private clinic. So he represented the perspectives of health care providers from both government set up as well as private clinic. Another specialist physician was retired CMO who opened his own clinic in his locality (in kakching sub division) and he was also the consultant physician of the patients network 'Diabetes self care society'. The third specialist was also retired CMO, working at his own private clinic as well as consultant physician of the NGO-Rural development society and international Lions club.

Table 5.1 Health care providers and characteristics

Health care providers	Sex		Sub total	Age range	Ranger of years in practices
	M(9)	F (9)			
General practitioners	2	2	4	29-35	5-2
Specialist (Medicine)	3	0	3	45-64	15-30
Nurses	0	4	4	30-45	5-15
Key informants	3	2	5	35-60	10-25
Indigenous healers	1	1	2	52-65	20-35
Total no of health care providers interviewed = 18					

Same was the case with general practitioners; they were full time employee as medical officer in district hospital and at the same time were also working at private clinics A and B when their duty was off.

Therefore, findings are presented generally as perspectives of health care providers rather than categorising them based on places where they work such as private or government health institutions. However, researcher tried to highlight the differences in perspectives as observed by her or as mentioned by the health care providers.

Table 5.2 Details of the health providers being interviewed

Qualification and position of the health care providers	Number	Work experiences
Specialist (MD, Medicine) With periodic training on diabetes care and management	3	Two were retired CMO, working as private physician at their own private clinics (Private clinic B and at Kakching sub division), one was senior medical officer at district hospital as well as working simultaneously at a private clinic (Clinic A) as consultant.
General practitioners (Medical Officers (MBBS))	4	One was serving as MO at district hospital for more than 5 years. Another two were at DH as MO from last two year and both of them were working at private clinic B. one MO was at DH for 3 years and also working at private clinic A.
Nurses (Bsc Nursing)	4	Two were working at private clinic B for five years and they also worked as pharmacist of the clinic and another two were at DH with 10-15 5 years of work experience
CMO of the study area (MD, Psychiatrist)	1	Serving as CMO at the study area for 4 years and practice experience of 30 years
Traditional healer	2	More than 20 years of practice
Key informants from NGO, Civil society organisation	2	One from NGO (Rural development society), another from International Lions club
Key informant from state health service	1	Working as additional director, State health department for 3 years with 20 years of practice experience.

Following sections of the chapter reported findings in different headings and sub heading based on themes arises from research questions and responses from health care providers.

5.2.2 Diabetes treatment practices and its meaning among the health care providers

Majority of the people seeking treatment from these health institutes (district hospital and private clinics) consisted of patients suffering from fever, diarrhoea, cold/cough, infections, joint paints or body weakness. Among these patients there would be 2-3 diabetes patients in a day. There were days where there was no patient. In district hospital, very few numbers of people come for diabetes treatment. There were less follow up by patients. However in case of private clinic many patients visited the clinic for diabetes check up.

Treatment practices were also different based on the work experiences of the providers. It was observed that most of the general physicians who were working for 2-5 years of experiences (as shown in the tables above) would treat diabetes patients as any other patients with acute medical problem. However those senior doctors who had been treating diabetes for a long time would treat them differently by checking their past clinical history and trend of blood sugar level. These senior doctors mentioned the motivational factor of health care providers as important component in diabetes management.

When posed question on diagnosis and suggestion for blood sugar check up to patients, most of the physicians said that if the patient was more than 40 years and reported general weakness, lethargic, polyuria or without any particular disease suspected, they asked them for blood sugar test.

It was observed that doctors had the general tendency to prescribed oral hypoglycaemic drugs (OHAs) when the blood sugar reading was high even for the patients coming for the first time. A trial of diet and exercise before starting OHAs was rarely given at many practices. It was explained by a general practitioner that if he does not prescribed any medicine the patient may feel that the doctor had not done anything in treating him/her. Doctors and nurses reported that most of the diabetes patients got lost to follow up after the initial visit or two. They stop coming to them

and they would go to other doctors or would follow traditional medicine or no treatment at all.

Common complications of diabetes that doctors and nurses observed were retinopathy and neuropathy. According to them, patients were not aware about complications and as there was no facility in both the district hospital as well as in private clinics in the study area, they referred cases with complication to Imphal. In district hospital they usually referred patients in state hospital such as JNISMS or RIMS. As for private clinics, they did not have any particular health institutes or diagnostic centres where they make reference. As reported by physicians and nurses from private clinic, their patients got treatment from wherever places they want. However, if patients asked for their recommendation, they provided their own suggestions.

Increase susceptibility of Diabetes, especially type II as perceived by providers were due to increase physical inactivity, high rate of motorisation, changes in transportation pattern leading to decreasing habit of walking, sedentary life style, younger people working more in office jobs which require long hours of sitting, increasing in many fast food outlets in local areas, changes from traditional diet which was mostly boil food to fried foods.

A senior physician and a key informant mentioned that increasing number of diabetes patients could be related with the increasing awareness of diabetes among the people as well as in health provider's community.

> *"This was there from before however, may be because it was not common phenomena, people were not that attentive about diabetes, same for health providers and doctors too. Nowadays because of increase awareness or at least diabetes becoming a common household name, it is getting diagnosed more and we also now usually ask for random blood sugar test to our patients, even though they do not particularly visit us for diabetes. But still, scientific studies say diabetes cases we diagnosed are only the tip of what is in our population."*

Three general practitioners and two nurses mentioned that specific food habit and eating pattern of study community as possible causes of increase in diabetes cases. It

is highlighted in following narrative by a nurse in district hospital, who was working in health sector for past 12 years.

> *"We eat three times in a day, our breakfast starts from rice till dinner time. Rice, commonly available and what we eat are locally grown with high amount of starch which is not good for sugar patients. We use mustard oil as it is also easily available and we have been eating this for long time. Foods are not taste good if not cook in mustard oil. You see, we are so used to eating tasty foods. And all tasty foods are enemy for diabetes."*

Another narrative highlights problem with portion of food people eat and timing of eating food.

> *"We eat in large quantities specially rice in dinner time. During lunch time people are busy with work so they cooked proper and variety of food in dinner time. After heavy dinner, we go to bed directly or sit to watch TV. This is the cause of increasing weight and obesity. "*

They shared that this food pattern and habit had been there since our forefather time and they are not recent phenomena. So, why diabetes is so common nowadays compare to earlier days? They further talked about different way of living now and then. In earlier days people were engaged in manual, physical work unlike present time.

Another social and cultural factor that health providers mentioned was very frequent social gathering which serves meals cook in lots of oil, salty, sweet items and uncontrolled food proportions.

They felt that though these food habits and social customs are rooted to our culture, patients and care givers should try to avoid it for better care and management of diabetes. In the following section, themes on barriers to diabetes management from provider's perspective are discussed.

5.2.3 Barriers and challenges in diabetes care as reported by the health care providers

Lost to follow up of the diabetes patients, very prevalent nature of doctor's shopping, lack of awareness, knowledge and motivation from the patients and their family as

well as from physicians, financial constraints, non availability of specialist services and lack of continue medical education, work load (shortage of time) were highlighted by the health care providers as constraints they faced in the management of diabetes patients. These barriers and challenges are presented in this section by categorising them as related to patients, health care providers, organisational and social/cultural related constraints. All the findings noted down in the following table 5.3 are as shared by health care providers during in-depth interviews.

5.2.3.2 Patients related barriers

I. Lost to follow up/Doctor's shopping, non adherence to treatment of diabetes patients

All the health care providers interviewed reported about poor follow up of diabetes patients. They expressed their dissatisfaction and said that after the first few visits patients did not to follow up. After they tried different other doctors or treatments such as herbal or spiritual related rituals they would come back only when there were complications or other medical problems. Doctors reported this behaviour as a barrier in successful management of the diabetes patients.

According to them reason for loss to follow up by patients was related to 'poor knowledge of patients and care givers' about diabetes, their 'ignorance and careless' about their health. Following narratives are quoted from the interview of nurses and physicians.

> *"Diabetes patients usually disappear after some visits. They take the medicine for sometimes and if they are relieved from the symptoms or feeling well then they stop taking medicine without consulting doctors and they do not come back for check up until they have some other problem"*

> *"They do not understand the chronic nature of diabetes. Patients have the hope of getting cure from diabetes by taking medicine. If they are not getting better soon, they would try some other forms of treatment like herbal or this spiritual prayer or they would go to some other clinic."*

Table 5.3 Barriers and challenges in diabetes care as reported by the health care providers

Categories	Barriers and challenges	Remarks
Patient factors	Loss to follow up, non adherence lack of knowledge/awareness among the patients and care givers, lack of motivation from patients, lack of trust between patients and doctors, financial constraints	Doctor's shopping common phenomena causing loss to follow up, Non adherence include not taking medicine continuously, not following diet plan, physical activities, knowledge components mentioned were not understanding chronic nature of diabetes, looking for cure, types of food, portion and preparation, patients feel that doctors prescribed unnecessary medicine, they look for alternative treatment option as they do not trust their doctors, not able to afford continuous treatment because of money but care providers said many patients who can afford also neglect treatment as they are lazy and do not care for their own health, consider this as ignorant behaviour.
Health care provider factors	Shortage of time for consultation due to work load, lack of motivation from care providers, lack of continue medical education, lack of working experience	Shortage of time was reported by physicians in district hospital, senior physician emphasised the importance of motivation from doctor as diabetes needs treatment for longer duration and continuous care

Organisational factors	Non availability of diabetes care services, long distance of health care institutions, lack of transport facilities, lack of diabetes specialist, non availability of diagnostic facilities for treatment of diabetes complications,	Lack of specialist doctor for diabetes treatment was reported by nurses and junior doctors. However senior doctors said that whether a patient go to a specialist or general doctor, it does not make any difference as diabetes care need major contribution from patients side.
Social and cultural factors	Food pattern/habits, cultural and social norms of frequent lunch gathering for every occasion in the community, blind faith and belief in spiritual way of healing, too much dependent on herbal treatment.	This factor was mentioned by many of care providers. Changing in food pattern was found difficult as it was rooted in social and cultural norm but they emphasised that people need to change if they want to be healthy. Many of them were not in favour of consulting traditional healer especially doing prayers and spiritual treatment. They felt that patients tried many of such practices and when things do not work with this treatment, they come to clinic with serious stage of diabetes with many complications which could have been avoided with timely medications.

"Patients would stop taking medicine for long time and when there are complications they come to the clinic and expect us to cure their illness. They said that due to financial problem they could not continue the treatment but I tried to make them understand that it costs more when there are complications so better to take care from before."

"Changing consultant doctor is such a fashion among the patients. They would go to whatever clinics or doctors other people say as good one. When nothing works out they would come back. It is very difficult for us to start a treatment after that as we have to give the medication according to what they have taken before"

From these explanations by health care providers non adherence to treatment was because of following reasons, patients felt better after taking medicine so they thought there was no need to take medicine or patients did not feel better soon after taking medication therefore they switch to other form of treatment or choose another physicians as they want to get cure fast. And financial constraint was also acknowledged by providers as a factor in non continuation of treatment. Though they mentioned financial problem, nurses reported that many of patients without financial difficulties also do not follow up regularly and they related this with lack of motivation and knowledge among patients and care givers.

II. Lack of motivation and knowledge of patients and care givers

All the health care providers agreed that there was lack of knowledge, awareness and motivation among the patients and care givers. They emphasised the importance of self care, role of patients themselves and family members in diabetes management. They felt ignorance from the patient side as major hindrance. Following narratives by the doctors and nurses highlighted this issue.

"This is an illness which needs lots of care from the patient side. Only the doctor's medicine cannot help them but patients do not know and they do not care also. They hardly follow what we suggest. If they drink alcohol, smoke or eat all the bad food. What can we do?"

"The effort has to come from the patients and their family; if they do not take initiative we cannot do anything. No matter what we suggest if they are not motivated they are not going to do anything about their health."

"Do you know what kind of patient is the hardest to handle? Those people who has some knowledge. Those with zero knowledge follow our advised, they trust us. But these people who has some knowledge but not the complete understanding, they questioned whatever their doctor suggest and they think that we are not treating them right so they would go again to another clinic or do something else by themselves. When nothing works they would come back."

Level of patients understanding and knowledge on diabetes care is considered as having a major role in the diabetes management. According to their perception and opinion they have different approach of treatment seeking. Therefore health care providers felt that lack of knowledge and negative attitude of the patients as a barrier in diabetes management.

III. Financial constraints

It was generally acknowledged by providers that lack of financial resources of the patients as a constraint in successful diabetes management. Many of the patients were not able to follow up or come for check up on the day doctor gave them appointment. A nurse in the private clinic narrated

"Sometimes patients come back for check up much later because they had to arrange money before coming to clinic. Only when they have money they come for check up"

Doctors also felt that their patients are having financial shortage but they have to treat them in best possible alternative ways.

"Most of the patients coming to the clinic are poor. They cannot afford those specialist treatments at Imphal. So we have to consider this factor when we prescribed medicines"

"Insulin is expensive. As she cannot afford it regularly, she stop taking for days. This again worsens her condition. So I had to put her on OHA"

A nurse who was also working as pharmacists in the private clinic with their own pharmacy shared with the researcher

> *"Sometimes our doctors prescribed them other vitamins and food supplements along with diabetes medicine. When they buy medicine they would asked to give only the most basic and necessary medicines as they did not have enough cash."*

Thus financial constraint is also mentioned as barrier in diabetes care and management.

IV. Lack of trust between the doctors and patients

It was highlighted by few doctors that patients tried different treatments and consult various doctors to cross check if doctors are treating them right. An instance about the use of insulin was mentioned by some of the doctors. If they put a patient on insulin they would not come back for next follow up.

> *"I have started insulin treatment for a patient since then he has not been coming for check up. This is very common. Patients do not want to get on insulin therapy. They have a false belief that insulin treatment has to be done in the later stage and once insulin is started, they have to use it for lifelong and it makes their condition worse. Even if we explain well they will not listen. They would say they heard about these from the people who are diabetic and already used insulin. So they would insist on OHA. If we do not prescribe OHA they would go to other doctors."*

A physician had to say this

> *"They would even check our educational background. In our clinic there is a senior doctor and we are new with only few years of experience. When they visit the clinic, if our senior doctor is not there, patients sometimes do not let us check or write prescription."*

This factor was mentioned mostly by junior physicians.

5.2.3.2.Health care providers related barriers

I. Time constraints and heavy work load

Lack of adequate time as a constraint in diabetes treatment is reported by physicians particularly when they are treating patients in OPD of the district hospital. For private clinics, though physicians mentioned about lack of time but it was not considered as much of a problem in diabetes care.

In OPD of the district hospital many other patients with different complaints come for treatment and they usually wait for a long time for their turn. So doctors felt that if they give longer time to one patient they would not be able to treat all the patients coming to OPD. Medical officers in the hospital shared that diabetes patients need to be educated well about the disease and its management as most of the management part is to be done by self care of the patients and their family. However, they cannot give the patients all necessary information as it consumes lots of time and they have to do their duty to other patients also as narrated by a MO at district hospital.

> *"Treating a diabetes patient in general OPD is difficult; it needs special care and time but as you see so many patients are in line. We have to take care of all of them before OPD timing gets over. Work load is too much sometimes."*

Dr. K of the private clinic B, who is also a MO at district hospital general OPD said

> *"The scene is so much different here and hospital OPD. Patients in the private clinic are motivated and interested in what we tell them. So we can spend enough time as there is no specific timing here"*

II. Lack of Continue Medical Education and limited working experiences with diabetes patients

Senior physicians talked about limited working skills of health providers especially when they have to deal with diabetes patients. They expressed the need to update their knowledge and skills on new advances made with medical technologies. It was observed that most of the physicians referred to booklets and information supplied by pharmacy companies. Medical representatives frequently visit clinics and advertised about their products and physicians refer to them and prescribed their products. Thus

private diagnostics and pharmacy companies influence in medical practices of health providers.

III. Lack of motivation among health care providers

Not only willingness of patients and their motivation in diabetes, motivation from provider's side and their effort were mentioned as one of the important factor in successful diabetes care and management. Diabetes being a long term, chronic condition which doctors and nurses are need to be in continuous touch with patients, health care providers should approach treatment of diabetes patients from treating acute illness and patients need to be motivated for their self care. They agreed that this approach need time and patience therefore doctors and nurses should be motivated. Lack of such motivation was reported as a barrier in diabetes care. This factor was shared by senior physicians.

5.2.3.3 Organisational factors as barrier in diabetes care

I. Non availability of Specialist diabetes care services

The issue of non availability of specialised diabetes care services and diagnostic facilities was mentioned by nurses and physicians. As diagnostic facilities like HbA1c test, kidney function tests, lipid profile test ect were not available in the district, patients were usually refer to hospital at Imphal to check up for complications and asked them to come back with the test result. However patients hardly returned for follow up.

> *"I refer my patients at diagnostic centres at Imphal for detail diagnosis and test to identify the complications but they would delay or do not go at all. One of my patients said he need to prepare mentally to go to Imphal and get the test done because going there means using whole one day. So having all the facilities nearby would make it easier for the patients."*

The problem of health care infrastructure and the distances that some patients have to travel to the clinic were acknowledged by health care workers in this study as a factor influencing the patient's clinic attendance and health seeking behaviour.

As contrast to this, senior doctors did not considered issue of non availability as a hindrance. Dr. Y who had been treating diabetes patients for more than 10 years and a medicine specialist with competent training in diabetes management expressed

> *"We are giving the same treatment as those specialists at Imphal. Patients and family members are all about going to Imphal. But even if the specialists prescribed you the best medicines, if the patients do not take self care of their own health and not following healthily living, no one cannot help them."*

This was also mentioned by a nurse working in a private clinic. The need of basic diabetes care facilities in primary care level was considered as more important than having more specialist care. Different opinions on services to be given were highlighted from the responses of care providers.

5.3 Opinion on use of Traditional medicines

There were mixed responses from health providers regarding the use of indigenous medicines. They were in favour of consuming herbs and vegetables which are known to be good in controlling blood sugar level and they also suggested patients to eat these herbs along with their meal everyday in right quantity. But they have different opinion about completely depending on these medicinal plants for diabetes treatment as claimed by traditional healers. Belief of the community people in spiritual prayers and eating or drinking products made from different plants which they believed the spiritual healers put the blessing to cure the illness was considered by doctors as harmful for diabetes management. They suggested this might exacerbate the problem because the healers asked the patients to stop allopathic medicines for their medicines to be effective.

As reported by health care providers, patients sought treatment from Traditional healers in different phases of illness. Some patients visited healers in initial phase before consulting biomedical care. If symptoms of illness were still there after taking herbal or other form of medicines, they go to hospitals. For some other patients, after getting biomedical treatment, if there was no rapid recovery, they go to healers. Sometimes they completely stop allopathic medicines or they were using both allopathic and herbal medicines. This health seeking behaviour of patients was considered as a hindrance to diabetes care by biomedical health care providers.

5.4 Perspective on better management of diabetes care

Health providers shared their views and perspective on how to improve and managed diabetes care in better ways. Themes came up during the discussion were:

I. Need of governments policy, program and diabetes clinic day in the district hospital with train health care workers on diabetes education and management:

Key health officials of the district felt that there is lack of government initiative in regards to NDC care.

> *"There is no policy/program in the state as of now on diabetes care. GOI had started it in phased wise to some states but till now Manipur is not yet included. Given the magnitude of diabetes patients coming to the clinic and hospitals and as we see in our surroundings, I think this is the time we do something for diabetes care, having a diabetes clinic day as in RIMS and JNIMS at Imphal would be good start. Nurses and doctors should be given training about treating diabetes patients."*

II. Education and awareness about diabetes prevention and care

According to the opinion of health care providers, patient's knowledge and understanding is the key to better management. Therefore, there should be government initiatives on mass awareness campaigns. Involvement of community based organisations, youth clubs, women groups along with patients and their families was mentioned as possible way to spread diabetes awareness at community level. They believed that increasing their knowledge and support from health care providers and family would help in better self care and successful management of diabetes.

4.5 Traditional healers and diabetes care

Different ethnic groups living together in Manipur such as Meiteis, tribals and Manipuri Muslims have their own traditional healing practices which have been transcending from generations and they prescribed folk medicines which are herbal, animal, organic products or mystic incantation. These practices are strongly rooted in society and cultures of these ethnic groups and people have farm beliefs in this age old healing practices. Traditional healers are still an important part of health care in Manipur, especially in rural areas where there is lack of basic health care services.

In this study, two healers were interviewed and both of them belong to Meitei groups. One is male which is known as Maiba in local Manipuri language another is female known as Maibi. They are known as local priest. Not only healing practices, they are engaged in various other cultural and social activities such as community prayer, rituals and spiritual related events. Their healing practices includes use of herbal/plants/animal/mineral products to prepare medicines based on local knowledge and practices of performing rituals such as praying and offerings to evil spirits.

Mr. P, age 63, was in the field of traditional medicine and healing for more 20 years during the time of study. He was believed to possessed occult power. According to Mr. P, his family was gifted with this knowledge from his grandfather's generation. It was inherited to his father then to him. He said treating an illness is based on principle which is applicable to all types of illness which he called balance of body energy/wind. When this balance is disturbed people get sick. So what he does in his treatment is restoring this balance with the help of prayers and offerings to the universe along with giving the natural integrants to the sick person which are supposed to be good for maintaining body energy. He performed healing practices at his own home and he was well known in the state that patients had to take appointment in advance and patients from all over the state come to consult him. Usually he advertised about his healing practices in local newspapers. He claimed that his preparations (herbs, animal product or minerals along with prayers and chants) can cure chronic illness such as arthritis, asthma, sexual dysfunction, and diabetes and kidney stone cases.

As for diabetes, he said there are many herbal products. As this is a diseases of frequent urination and more sugar in blood, herbal medicine to be used are those plants which help in decreasing water released from the body. He studied from his father about different varieties of plants and herbs with medicinal value. He used these plants and their valuable parts to extract medicines. He would put his prayers and chants in these medicines and give it to the sick person to drink. He acknowledged the importance of consulting doctors and allopathic medicines but he said if it is still in early stage such herbal medicine can always cure illness.

Another interview was with local herbalist with experience of 22 years in traditional/folk medicine healing practices. She was 68 years old. She was more of

local based providing healing practice in her own community. She usually diagnosed and treated everyday illness. She said she did not prepare particular herbal medicine for diabetes only but all common ailments to boost body immune system and to give energy or to purify blood.

5.6 Summary

This chapter described the existing health care services of the study district and its nature in relation to diabetes care. In the first section of the chapter we found out the mixed health care services government hospitals as well as private clinics run by individual doctors. Along with these the district also has other forms of diabetes care service provisions like patients network, health camps organised by civil society organisations and pharmacy companies. In partnership with a local NGO in district, world diabetes foundation was also implementing its project on prevention and care of diabetes. Thus the interaction of different forms of services provisioning was highlighted in this chapter. In the second part of the chapter perspectives of health care providers was explored. They reported about loss to follow up, low compliances of patients to treatment, switching of doctors, structural issues of distance and non availability of services, financial constraints and lack of motivation, knowledge and awareness of patients and family members about diabetes, lack of trust on doctors by the patients, limited skills of health providers due to lack of continue medical education as barrier in successful management of diabetes patients. For the better diabetes care they feel that government should play a major role in establishing diabetes clinic or diabetes day in the OPD of District hospital. There should be mass awareness campaigns as well as diabetes education program for the motivation of patients and health care providers. In the last part, views on traditional healing practiced by biomedical health care providers as well as by healers themselves on diabetes care are presented.

CHAPTER 6

Diabetes Self Care Society: a patients' network in Thoubal District, Manipur

This chapter presents a case study of diabetes patients' network in Thoubal district, Manipur. The findings presented in the chapter are based on the interview of key members of the network, focus group discussion with the members as well as information gained from the interview of non members who belonged to same locality where this patients' network was established. Official records and documents were also studied to collect information on socio-demographic profiles of the members and activities conducted earlier. Observations of activities conducted like health camps, awareness campaigns, monthly meeting and gatherings were also done. This chapter is organised into following sections. First section presents how the network was formed, objectives, who were key members and profile of the registered members. Findings on activities of the network and how these activities are conducted is discussed in the second part of the chapter. Third part is regarding the difficulties and barriers faced by the members. Next section focuses on this network as possible platform for social support in self care of diabetes. This section is presented based on the findings of focus group discussion of the selected members. Lastly, perspectives of those diabetes patients in the community who were not member of the network is discussed to provide larger view on patient network and its potential benefit in diabetes care.

6.1 Diabetes self care society (DSCS), Kakching Thoubal District Manipur: Formation, objectives and members

6.1.1 Formation and objective of DSCS

The patient network, DSCS is a community based organisation which was established in the year 2002 by a group of friends who all were diabetic. They normally talked about their health conditions when they met for morning walk and evening tea. They shared their experiences with the consultant physicians, information on treatment or self care advices. They felt that many people in their locality, friends and relatives

were suffering from diabetes. So this group of friends thought it would be a good idea to have a common platform where all of them can come together and help one another with coping of diabetes. Later they contacted doctors in their community to purpose this idea. The doctors agreed to help with establishment of network and organising health check up activities. Among these doctors some of them were also diabetes patients. During this time, a senior medical officer who had a home based clinic happened to talk to a medical representative (MR) of a private diagnostic clinic in Imphal regarding this community based network. The MR offered to help the patients' network in organising health camps. After having several meetings, they drafted the objectives, work plan, activities which could be conducted and how to approach community to get in touch with other diabetes patients. They also talked to local political leaders who was also a diabetes patients and with his help, the network was registered officially as 'Diabetes self care society '. People who were already the members of the network invited other diabetic patients they know in their neighbourhood to join them. Thus through the social net work of the patients, members were recruited. Many of the members were also joined by themselves. The members contributed a sum of Rs. 100 as fund for the network when they joined the network. There was no office place for this network; all the activities were conducted in local community halls or schools. Administrative and works related meetings were usually done in the house of one of the key members.

Objective of the network was to have common platform for diabetes patients in the community to share knowledge and information on diabetes, to help in coping with it and for easier access to diabetes care health services.

6.1.2 Key persons who were involved with the establishment of DSCS

At the starting, there were 6 members who were involved in the proposal of establishing this patient network. They all were well educated and working as doctors, lecturers, engineer, and political leaders in their community. The Member of legislative assembly (MLA) of this locality and a senior medical officer was elected as president and vice president of the network. The secretary played major role in organising activities of the network and maintaining records of these activities and members. He was a lecturer in Manipur University. He was elected as secretary because he was young in the age of 39 and had more knowledge on diabetes and was

willing to work for DSCS. Members could approach him for queries and any assistance.

6.1.3 Members of the society

Till the time of data collection there were 139 members, 84 male and 55 female. A register was maintained to keep all the records of the members. It had particulars of the members: name, address, date of birth, occupations and educational status as shown below in table 6.1. Each member was provided with an identity card which had detail on personnel information and status on diabetes.

It was revealed from the table on socio demographic profile of the members that there was more participation from the age group 40-50 and 51-60, both in the case of male and female. There was low participation from the younger generation. When discuss about this with the key members, they thought this could be due to the fact that diabetes affect more in the age above 40. However, according to the secretary in early time of the establishment of this network younger people were hesitant to be part of it as they did not want to publicly reveal about having diabetes. They also had difficulties in mobilising female patients. During the time of registration of the network there were 41 members in which only 8 were females. The secretary expressed that this situation had been changed recently with active participation of local youth clubs and women organisations in the network's activities.

Most of the members were educated, 53/139 had bachelor degree followed 38/139 with secondary education. Majority, 131/139 were Hindu and belonged to schedule caste. This is due to the social composition of the community where the DSCS is located. The network is at the Kakching panchayat of the Kakching sub division which is dominated by the schedule caste and Hindu population. Detail information regarding the occupation of all members was not available. However, study of those available information showed that nature of occupation was varied from government employees to small business owners like groceries shop, local restaurants, house wife to daily manual workers like farmers, construction of houses and roads.

6.2 Activities and organising of the activities

6.2.1 Activities

Activities usually conducted in this network were health check up camps, awareness campaigns, meetings and discussions among the members. There were no specific activities to be conducted and timing for activities was not fixed. This patient network is a community based voluntary organisation initiated by patients themselves, without any funding or guidance from the local as well as state government. There was no office building, no binding rules or activities. All the activities were conducted according to the availability of resources, time and convenience of the members. Thus, there was flexibility in how the network functions.

At the time of study, it had been already 12 years since the foundation of the network. There were few members at the first few years therefore activities were less. Meetings and discussions were held regularly along with the doctors in their community. Health camps and awareness activities were rarely conducted during that time. The secretary of DSCS, Mr. Y shared that

> *"During those time Diabetes was not so known to people as it is now, it was just another disease like others....when we approach the community to support DSCS, they were like 'there are so many diseases but why diabetes?'. For almost 2-3 years, it was only 10-11 of us. This network was inactive... except for the monthly meeting and discussions with doctors from our locality."*

I. Meetings / Gatherings

Meetings were held once in two months or whenever convenient according to free time of majority of the members. As there was no particular space for the network, such gatherings happened in the house of the key members or other members who had big spaces in their house. It was a regular activity at earlier years of DSCS. However, the secretary of the network told the researcher that since past few years, this meeting had been irregular as they all got busy with their personnel work.

Table 6.1: Socio Demographic Profile of the members

Total number of members		139		
No. of males		84		
No. of females		55		
Age groups		Male	Female	Total
	30-40	11	3	14
	40-50	24	13	37
	51-60	24	18	42
	61-70	16	5	21
	71-80	14	1	15
Education	Illiterate	17		
	Primary	20		
	Secondary	38		
	Graduate	53		
	Post graduate & higher	11		
Religion	Hindu	131		
	Muslim	3		
	Christian	5		
Caste	Schedule Caste	131		
	Schedule tribes	5		
	OBC	3		

In the meeting, doctors talked about diabetes, how to care and managed diabetes at home, their diet plan. Among the members, they shared their illness stories, physical conditions; they talked about the psychological and emotional problems. During such gatherings, consultant doctor of the network as well as other members with diabetes for longer duration shared their knowledge and experiences about diabetes management. Thus, one of the important activities was being a social and emotional support system to the patients and families in the community as narrated by a member with 15 years of diabetes who had been part of the network for almost 8-9 years.

> "*When people are diagnosed with Diabetes, they are very anxious and tense; psychologically and emotionally disturbed, they have lots of questions and confusions about the illness, diet or which doctor and where to go for treatment. During our evening gatherings, we talked about all these issues and tried to help them, calm them. Mostly they asked about type of food which are not good for sugar problem and which are good. Thus, they are at least somehow relieve and lessen their burden"*

Thus, meetings and gatherings were an important activity of the network which extended informational, psychological and emotional help to the diabetes patients in the community.

II. Diabetes Health camps and awareness activities

Diabetes health awareness campaigns, free health check up such as sugar test, identification of complications and arrangements for further treatments were core activities of the network. Health camps were conducted actively in the later years of the foundation of the network around 2010-2011. This was time when many diabetes patients become member and started to involve in DSCS. During such camps, patients and other people were given the opportunities to interact with the doctors and nurses, to discuss about their individual health problems and other queries. If any diabetes complications were identified, arrangement for further referral and treatment was made. Not only the members, other people in the community also participated in such events and they got the opportunities for free diagnosis.

It was observed that diabetes medicines and glucometer were sold in discounted amount. Demonstration on how to use glucometer at home was given by nurses and technicians involved in health camps.

The network had a consultant doctor who himself was a diabetes patient and a member of this network and a senior medical officer in the health department of Government of Manipur. He was from the same locality where the network located. He had his own private clinic at the Kakching Market. So, before going to Imphal for further specialised treatment people usually consulted with him first.

With the money contributed by the members, DSCS kept a glucometer and strips for sugar test at home of the secretary. Therefore instead of going to clinic every time to monitor blood sugar, they used to come to his house. It saved money as well as inconvenience of going to the diagnostic clinic.

Thus, the network act as a connecting link between the community and the health professionals by provides technical, medical assistance as well as gives informational, social, emotional and psychological support to the members and other patients in the community. Such informal, community based organisation played a significant role especially where there is lack of health care services with no attention from the state authority as in this community. Therefore members and community people expressed gratefulness for arranging such health camps especially diagnosis and check up for complications. These perspectives of the members are given in details in later section of the chapter.

6.2.2 Organisation of the network's activities

There were collaborations of the network with various pharmaceutical companies and private diagnostic clinics to conduct health camps and awareness. In the earlier phase, network did not get much attention from them therefore due to lack of resources, manpower and support most of the activities were limited to meetings and sharing with their consultant doctor.

Health awareness and check up camps were organised in collaboration with different pharmaceutical companies like Indo co, Leupin, Norva Nordisk and many other private diagnostic centres in Imphal. Key members shared that they got in touch with these private companies and clinics through doctors in their community. Medical

representatives (MR) of these pharmacy companies used to visit private clinics of these doctors. One of senior doctor happened to share with a MR about DSCS and he showed the interest of organising diabetes health camps in the community through this network. After discussing with key members, they decided to conduct free diabetes check up camp with the help of pharmaceutical company of this MR.

A Key member recalled that

> *"That was the first time that our patient's network had organised diabetes camps. We felt happy for this opportunity.....that feeling of achieving something better because earlier all we could do was just talked among ourselves."*

This was happened in 2006, 4 years after the foundation of network. Later on they organised such health camps once in 3-4 months. Usually their consultant physicians contacted the MR and he arranged all the technical requirements such as hiring diabetes specialists, diagnostic tools, providing educational materials for awareness campaigns and medicines. These pharmaceutical companies were partners with private diagnostic centres and private hospitals in Imphal.

They organised health camps with this first pharmaceutical companies for around 3 years. Later they had opportunities to interact with other companies and organised health camps.

During the camps pharmaceutical companies involved in organising the activities, supplied medicine in subsidies rate. As told by one of the key informant

> "*For instance one tablet of Metformin cost around Rs.3 in the market but these pharmaceutical companies sells them in half of the price. So for a month one needs 60-62 tablets. So total cost comes around Rs 180 and when we buy from them it comes to Rs. 90-100 only. Thus many of us could save money and we do not have to go to pharmacies and look for these medicines."*

An interesting and worth noting points to be mentioned here as observed by the researcher during one of such health camp was the process of referral system. If there were any complications detected, the diagnostic clinics or the pharmaceutical companies referred them to the private clinics or hospitals which were partner with

them. They provided the patients with a referral form and told them they would get discount and could get the treatment in subsidies rate. This was very common for the retinopathy complication. They help patients in taking appointment for operations like eye lens replacement for the serious complicated patients. Thus, private hospitals were able to approach patients in the community to avail services in their hospitals through such organised platform of patient's network.

If any patients in the community who were not member of the network want to join the camps they were requested to contribute some money like Rs.30-50. During the organisation of such camps local political leaders and those in financially well to do family donated money.

In the recent years, there was active involvement from the community. International Lions club of Kakching Branch had been helping them and camps were being held in collaboration with youth clubs and women group of the community. Local people also actively participated in health camps. For instance, those people who had stationary and photo state shop volunteered to supply the necessary stationeries, making flyers and those who had shops that sells eatable and tea volunteered to serve the refreshment. Thus they received different kind of necessary assistance from the community to make programs and activities successful. As they did not have their own spaces or office, such camps were conducted in local community halls.

According to the responses of key members, there was equal participation of both male and female members during camps. However, it was observed that though female members did come for seeking health care services their involvement in organising camps was not active. It was notice from the activities records of the network that with the active involvement and partnership of private pharmaceutical companies, much of the network's activities were related with medical treatment and care of diabetes. Meetings and gatherings which were source of emotional and psychological support for patients were infrequent during these times. When inquired to members about this change some of them said they did not realised about it, but they were okay as they got services from health camps..

Points that could be highlighted from above findings are connecting link made by patients' network between the community and heath care providers which are actually a means for people living in place where there is lack of health services. Second point

is in such context where there is no role and interest from local/ state authorities, private clinics and pharmaceuticals companies gained their customers in a much organised fashion and they made a channel through this network to enter the community directly. Third point is how the active involvement of clinical care, doctors and pharmaceutical/ diagnostic centres undermined and neglected the importance of social/peer support like psychological and emotional sharing members used to have earlier.

6.3 Difficulties and barriers

According to interview of key members, when the network was first established (2002), they did not received much co operation or positive response from the community as people were not aware about diabetes and its consequences. They showed least interest in being a member. One of the key informant and founder narrated

> *"Some people even commented that what is the use of forming such platform and we are just trying to collect money from people."*

Later on when the network started to organise health camps, people found it helpful and useful. Many of them came forward by themselves. So, one of the main challenge and difficulties was getting co operation and recognisation from the community at the starting.

One of the hindrances mentioned was lack of the space or meeting place. If they want to use community hall they had to take prior permission from the responsible authorities. So they had to conduct their meeting at house of the member who had larger space or office of the youth club was used.

Another issue raised was lack of financial assistance and other help from the side of Government. Because of this reason they had to depend on other private pharmaceutical companies.

Even though details about the socio demographic data of the members were maintained properly, there was no record on the clinical history of the members. When inquired about this to the key person specifically to the secretary of the network, he replied

"I have thought about this however it is not an easy task for one person to collect all these information and keep up to date clinical profiles of all members, there need to be co operations from the members as well as other key members.....we need strong motivation to carry on the activities…it is really not easy sometimes as we are a voluntary organisation without any assistance from any other NGOs or governmental organisations."

Even though there are many positive effect of peer support, potential barriers are highlighted in this study.

6.4 Patients' network as a platform for social support in self management

This section of the chapter presents responses obtained from four focus group discussions. Groups were separated for male and female, active members as well as non active members. A total of 25 members were included in the FGDs. Based on their responses, analysis was done on their experiences of how such network can be function as platform for social support in diabetes self management. This is supported by information shared and gained from the interview of key members. This provided a deeper understanding on benefits and assistance gained by the community from the network and examine how far having such patients network can be use as a platform for social support, coping, to generate awareness, self management education by understanding and analysing the people's response and involvement in the activities.

Groups were asked to share their experiences and opinions on the activities of the society, if they find it useful or any kind of help in the management of their illness. It was revealed that not only getting assistance in medical care, they were more happy with the social, psychological and emotional support they received from each other. They felt that they always had someone to talk about their illness and get the positive energy that many others were also suffering from diabetes and living well even after 10-15 years of having diabetes.

From their responses the kind of support they receive from patients' network can be analysed from different dimensions such as emotional support (the need for encouragement), informational support (identifications of symptoms, knowledge on self managements), clinical or technical support.

6.4.1 Emotional and psychological support

During the FGDs of female members, social support in form of emotional and psychological was discussed with more enthusiasm as compare to male group. They agreed that "we feel like we have someone to talk about our illness".

Following is a narrative by a female member aged 48, small shop owner in Kakching Market, who has been diagnosed with diabetes 5 years ago.

> *"When I was first diagnosed with diabetes, I thought why me? I was with lots of anxiety, tense and my heart was so heavy, because from what I know diabetes is a very dangerous life long illness, one has to live whole his/her life with diabetes, it needs lots of money for treatment, very expensive, we have to avoid various food items….I was worried about my family, children and all the management necessary for the shop. Then after some months one of my neighbors took me along with her to an evening gathering. There I had the opportunity to meet other Diabetes patients. It was such a good feeling, talking to them and knowing that there are many like me, perfectly healthy. Later on I always try to be part of the meeting."*

This narrative highlights the emotional, psychological support she received from the fellow members. It also acts as source of information for the members.

This network also acted as a channel for relieving stress for members. A male member had to say

> *"Our body do not feel good but people do not understand when we say this. We look healthy so they do not take our illness seriously...this happen even in our own family. Since you are not well, you get annoyed, you feel neglected....but here we understand each other, I relief my stress here talking to members".*

Thus, this network was a medium for members to communicate with each other and gained emotional support.

6.4.2 Informational support

Most of the members agreed that having such a network in the community was beneficial for them. Information on various aspects of diabetes treatment, self care and management were exchanged among the members. Information shared mostly were on topic of which hospital/clinics, doctors should they consult, how to make appointment and how much money do they need to arrange. They shared with the researcher that there were no diabetes specialist doctors/clinics in their community and even in whole district. Doctors in this study area were general physicians therefore they felt that going to clinics in Imphal was better choice. Due to the distance and inconvenience of transportation to go to Imphal, they wanted to make sure they visit the right doctors. Members who had already visited a specialist shared with others about working days and timing of the clinic.

A member said during FGD that

> *"Going to Imphal is a whole day task; we do not want to go there simply. So we better arrange everything like whom to consult, what time to go, how much money to be arranged. This way we can have a useful day"*

Another member shared

> *"Some of us had been consulting good doctors for diabetes treatment and we had good experience with them, treatment was satisfying. We casually talk to our members about such experiences whenever we meet and if they want they also go there for treatment."*

Further, they talked about the comfort level among the members. As they knew each other through the network, they could approach one other easily. This was mentioned by a member and most of them agreed about this benefit.

> *".....Generally people do not want to talk about their illness, who want to tell others that they are sick, you know it is not really a beautiful thing to share. But, here I feel comfortable talking about it, may be because we all know each other as diabetes patients."*

Another information they felt important and which many of them talked about during FGD was on food such as "which herbs and vegetables are good for sugar control,

which type should they avoid, how do they have to maintain their diet". Knowledge on locally available herbs and plants which are suppose to be good for reducing blood sugar level, where can they get these herbs, how to prepare were commonly mentioned by the members during discussion. They exchanged information on whose gardens in their locality have those herbs and how to use them.

However, it was observed that during the discussion, very few members talked about exchanging information on understanding of symptoms and possible complications.

Another important observation was differences in type of information shared by female and male. Topics on availing health care services were brought up by male members where as talks about food, how to cook and prepared local herbs were mentioned mostly by female members.

In spite of having such positive support, there are possible negative aspects. During the discussions, members also mentioned about the wrong information, confusions created from the interaction. Especially they talked about confusion over type of food and exercises. It was equally expressed by both male and female members.

One of the member, aged 52, male, living with diabetes for a year and half had to say that

> *".....having such a platform is obviously a good start for the patients in the community but (little hesitant)...as the saying goes 'many mind and mouths lead to many issues and confusions', many people are there so one will say this food is good, other will advice not to eat and again another will say 'no no if you take in little quantity it is okay'....for me this creates more confusions rather than getting a clear information."*

Another small business owner lady, aged 44 with 3 years of diabetes shared that

> *"Everybody has their own way of taking care of themselves; even the doctors and hospitals which we want to go for the treatment are also dependent on how well you are comfortable with the doctor and his treatment. Sometimes after meeting them (other members) they will say 'Dr. X is good or Y gives lots of unnecessary medicines…' especially when all the women are gather it is like a drama scene.....so it makes lots of confusions. I also want to get well*

soon so once I changed my physician to another one. Then the new doctor gave me lots of new medicines and made me run through so many tests. Even after doing all these I was not feeling much good so finally I decided to go to my old doctor. There again, he scolded me for discontinuing the medicines…so I feel it is much better to listen to your doctor only"

As the above narratives indicate, support may not always be the positive way.

6.4.3 Technical or professional support

Members expressed that activities of the patients' network on organising health camps and awareness campaigns were beneficial for them as attending such health camps provided them the opportunity to consult diabetes specialists in their locality itself. Services on free sugar check up, diagnosis and identification of complications were appreciated by many of the members.

A male member, aged 38, school teacher, having diabetes for 7 years and member of the network from past 5 years narrated his experiences of being part of patient network,

"I think health check-up camps conducted by DSCS are very useful, especially when they diagnosed and identify the complications of diabetes. For instance, eye check up, foot ulcer, kidney, HbA1c level ect. Because even if we know that diabetes leads to various complications, sometimes due to our daily work or engage in so many things, we tend to overlook this fact and do not care much. More over all the clinics and hospitals which have these diagnostic facilities are at Imphal which is again 40 kms away from our place and it takes whole day to go there, get the appointment, do the test, and wait for the result. Therefore, we go to clinics in Imphal only when we are really not well. During the camps physicians and nurses tell us about what we should do next and arrange for treatment at Imphal. So, I think, if the network can arrange such health camps regularly it will be beneficial for us."

This narrative highlights that patients network could be a clinical link between patients and health care providers. It also shows that even when the patients have knowledge about the illness and complications, lack of availability of health services and distance becomes a hindrance in treatment seeking of the patient.

Not only providing data on various aspects of supports and benefits members gained from the activities of the network, separate FGDs for male and female members reported different themes on support as perceived by them. For instance, FGDs of male members felt that they got information and support related with health care services while female members reported more support on emotional and household level diabetes care that is management of diet and foods. This difference highlighted the need of different approaches of diabetes care, different needs and meaning of diabetes among male and female patients.

6.5 Response from diabetic patients in the community who were not registered member and FGDs of members who were inactive in networks activities

These groups of diabetes patients were included in the study to provide a comprehensive picture on network's activities, perceived benefits and support from the perspectives of those patients in the community who were not part of DSCS or inactive members.

Through the network of the patients who were registered member of DSCS, 5 non member patients from the same locality were recruited for the interview. They were asked about why they were not part of DSCS. All of them replied that they heard about this patient network and there was no specific reason for not being a part of it. One respondent commented,

> *"Actually I do not have any particular reason of not joining…Yes, I know about this organisation but even without being a member we can just participate in those health camps by paying some amount of money…I know many of friends and neighbour who are registered. But I haven't given much thought about this organisation until you mentioned…"*

However, 2 patients commented about revealing one's sick identity.

> *"What is the point of collecting all the sick people and why one would have to show in front of all people in the community that we are suffering from diabetes. We just have to take care of ourselves."*

> *"People look differently on you if you are sick, who would want to feel that kind of pity feeling from others."*

During the focus group discussions of inactive members, they said that lately network's activities were not regular and they became a member though their friends without much thoughts on benefits. They mentioned that they were not comfortable about talking their health with others. Therefore they did not participated in networks activities.

These responses highlighted uncomfortable, social stigma, different views on being open about one's health and diabetes.

6.6 Summary

This patient network was established by a group of friends who all were diabetes patients along with doctors in the community. Medical representative of pharmaceutical companies which were associated with these doctors agreed to help in organising health camps and other activities of the network. This was how the patient network comes into existence. Objective of the network was to have common platform for the diabetes patients in the community to share knowledge on diabetes care and management, to help in coping with the illness. Till the time of study, it had 139 members, mostly in the aged group of 40-50 and 51-60. Activities includes monthly meeting of members along with doctors in their locality, sharing of illness stories, emotional, psychological problems, sharing of knowledge and experiences in diabetes care. Other activity was health camps and awareness lectures in collaboration with pharmaceutical companies and doctors from private hospitals. During such activities, these companies sold medicines in discounted rate among the patients, detected diabetes complications and made arrangement for further treatment in the hospitals they were associated with. Not only this technical or professional support, according to the members this network was a platform for social support in form of emotional as well as psychological. Difficulties and barriers were also reported were lack of financial resources, co operation from the community at earlier time well as local government, lack of spaces and infrastructure for regular meetings and gatherings.

CHAPTER 7

Discussion and Conclusion

This study attempted to bring out the social dynamics of NCDs care and management through a case study of diabetes in Thoubal district, Manipur. By analysing the interaction and interrelation of study findings in different levels: micro level (study of patient's perspectives, practices, need and difficulties in diabetes care from their own social context), meso level (study of service provision in the study area, health providers perspectives in diabetes management and role of patients network, NGOs) and macro level (larger policies and program of NCD care), the present research work aimed to explore diabetes care and management practices of patients and care givers in different social context and interaction with available diabetes care services, health care providers and factors influencing it.

This study was informed by gaps in literature on social context of diabetes care in India. Diabetes management strategy in India at the national policy level focuses on risk factors reduction, promoting healthy life style, educating people on healthy living, early detection and diagnosis. Various researches conducted in different regions of India and community level studies on diabetes care reported about lack of knowledge of patient as well general population on diabetes leading to delay in diagnosis and barrier in successful management. Therefore recommendations are often made on developing diabetes education program, making general population and patients aware about diabetes risk factors, prevention and management. Though it is acknowledged that good knowledge and awareness are important component in better health seeking behaviour and self care, other studies have shown that having knowledge and being aware only do not necessarily lead a patient to better management and health seeking. Another body of literature on barriers in diabetes care identified various factors related to patients such as financial difficulties, non adherence to treatment, loss to follow up, frequent changes of consultant doctors, not adhering to diet and physical activities. Organisational factors like geographical distribution and location of health care services, non availability of diabetes care

services, inaccessible, distance, lack of transport facility and work load of health care provider are also highlighted as barriers in diabetes care.

With the increase of health inequality across the globe a substantial body of research work have been done that show material and social deprivation as a linkage to incidence and prevalence of disease and access to care and treatment outcome. Studies have shown that social determinants of health which comprises of individual social characteristics such as age, gender, caste, class, education status, occupation, how a person live, his very day life along with his environment and society/community, larger political economic characteristic of the country he lives interact with one another and influence their health seeking behaviour, treatment and health outcomes. Low socio economic position and its association with adverse health outcomes for persons with diabetes and other chronic conditions were demonstrated in some literature (Brown et al. 2004; Raphael et al. 2003). This calls for deeper analysis and consideration of social realities of an individual life for management of ill health apart from just giving bio medical treatment especially when it is chronic conditions.

Literature on diabetes highlighted that diabetes is predominantly treated as medical problem and study of the patient's subjective experience in the process of diabetes care is often neglected (Graffigna et al, 2014). The main focus of diabetes management come from the medical understanding and practices which emphasizes the physiological disease and dysfunction while separating the illness experiences of patients. This can become a complex issue particularly in the present situation of India's health care system where emphasis are given more on private and tertiary health care and diabetes care could be predominantly specialist, private and tertiary care giving services to high class patients thereby neglecting patients from poorer section of the society (Bal, 2000). This trend might lead to over medicalization and problem of diabetes care to be answer by technological solutions by separating the importance of social realities of patient's life with diabetes and their illness experiences.

It is said that problem patients or people face lie within the complexity of whole social system and dynamics that constitute the matrix of their existence (Sagar, 1999). It has been suggested that studies from the patient's perspectives are important in

order to understand causes and developed better diabetes management strategies at a subjective, inter subjective and structural level (Kolling et al, 2010). In this conceptual frame work, this research work studied diabetes care and management of patients and care givers in their own social context, everyday life and their interaction with available health care services and providers.

To achieve this objective data was collected using qualitative research design among patients from various socio economic background and different clinical and treatment profiles from government hospital, private clinic and community. Their care givers and health care providers were also studied. Study of diabetes patient network in the district provided an insight into how patient network can be used as a platform for community involvement and social support in diabetes care. Over all study of diabetes care service provision in the study area was also conducted.

This chapter is organised into following sections: summary of findings, discussions on major findings of three chapters, study implications followed by conclusion and recommendations.

7.1 Summary of major findings

The current findings have been presented in three chapters (Chapters four, five and six), organised under specific themes addressing the main objectives and research questions of the study.

Chapter 3 explored the care and management of diabetes among the patients and care givers. The concepts of care and management in this study are defined as to include all the activities of the patients, their family members and/or social networks and health care providers that are aimed to keep diabetes under control following diagnosis. For the effective care and management understanding patients knowledge and perceptions on diabetes care, health seeking behaviour, challenges they faced and their coping strategies need to be discussed and detail findings on these aspect has been presented in chapter four. The finding suggested limited awareness and knowledge about diabetes and its management among the respondents. Even though majority of them heard about diabetes before diagnosed, they were unsure about causes and symptoms. Certain level of uncertainty was reported by respondents with regards to preventability, curability or treatability of diabetes. Section three

highlighted the health seeking behaviour. Most of the patients sought treatment from the private clinics and doctor's shopping was a common phenomenon in which patients described as their way of looking for better treatment which suits their body. Follow up care and adherence to treatment was low. Most of the patients and care giver stick to taking allopathic or herbal medicines, avoiding sweets and oily foods as their self care practices. Use of traditional medicine and consulting healers or herbalist was in consistent with cultural and social norm of the community which is also influenced by the family members, friends or healers themselves with the promise to cure the illness. Section four examined the difficulties and barrier in seeking treatment. Challenges faced by the patients and care givers were at personnel level that is lack of financial resources and affordability of medical care as well transportation cost due to distance of the clinic, health services level that is non availability of diabetes care services, lack of adequate time to consult doctors, long queue and waiting time, affordability and availability of OHA and insulin. Apart from this, due to social norms and tradition, female patients highlighted the issue of need of someone to accompany them if they are going for treatment at a hospital located in the capital city Imphal, which is far from their village. Challenges in self care practices at home such as dietary adherence was also reported due to lack of financial resources, social and traditional way of food culture and eating habits. Patients experience and interaction with health care providers, their own illness experiences and logical understanding of diabetes along with financial capability, socio economic status of the patients, availability of care services and medicines influences care and management strategy and practices of patients and care givers. Depending on family or social network for emotional, psychological and technical support was observed from the study. Some of them cope with the illness in the form of spirituality, fatalism, by having leisure time. Impact on the life of family members due to diabetes was notable burden in the form of emotional and psychological well being, financial condition of the family, and high level of distress, negative impact on the work or studies and leisure activities.

Chapter five described the existing health care services of the study district and its nature in relation to diabetes care. Findings show the mixed health care services, government hospitals as well as private clinics run by individual doctors. Along with these the district also has other forms of diabetes care service provisions like patients

network, health camps organised by civil society organisations and pharmacy companies. In partnership with a local NGO in district, world diabetes foundation was also implementing its project on prevention and care of diabetes among the school children, teachers and their parents. Findings on perspectives of health care providers reported about loss to follow up, low compliances of patients to treatment, switching of doctors, structural issues of distance and non availability of services, financial constraints and lack of motivation, knowledge and awareness of patients and family members about diabetes, lack of trust of doctors by the patients, limited skills of health providers due to lack of continuing medical education as barrier in successful management of diabetes patients. Traditional healing practices, using herbal medicines were common health seeking behaviour. These practices are strongly rooted in society and cultures and people have firm beliefs in this age old healing practices. Healers are still an important part of health care in Manipur, especially in rural areas where there is lack of basic health care services

Chapter six presented a case study of diabetes patients' network in the study area. This patient network was established by a group of friends who all were diabetes patients. Medical representatives of pharmacy company who were associated with doctors in the locality agreed to help in organising health activities of the network. This was how the patient network came into existence. Objective of the network is to have a common platform for diabetes patients in the community to share knowledge on diabetes care and management, to help in coping with the illness. Till the time of study, there were 139 members, mostly in the aged group of 40-50 and 51-60. Activities includes monthly meeting of the members along with local doctors, sharing of illness stories, emotional, psychological problems, sharing of knowledge and experiences in diabetes care. Other activities are organising health camps, awareness lectures in collaboration with pharmaceutical companies and doctors from private hospitals. During such activities, pharmacy companies sold medicines in discounted rate among the patients, detected diabetes complications and made arrangement for further treatment in the hospitals they were associated with. Not only this technical or professional support, according to the members this network was a kind of social, emotional as well as psychological support for them. . Lack of financial resources, co operation or positive responses from the community as well as local government, lack

of spaces and infrastructure for regular meetings and gatherings are reported as difficulties and barriers..

7.2 Discussion of major findings

This section discusses the principal findings of the current study, highlighting their implications for policy, research, management and control of diabetes.

7.2.1 Diabetes care and management

7.2.1.1 Knowledge and perceptions on diabetes care and management

Comprehensive knowledge and understanding on diabetes, signs and symptoms, its causes, treatment and complications were found to be lacking among the patients in this present study. Several studies conducted in different part of India highlighted about lack of knowledge on diabetes care among the diabetes patients as well as in general populations as presented in review of literature in chapter 2. In the current study many respondents had experienced the classical signs and symptoms of diabetes however more than half of them were not aware that those signs and symptoms are related to diabetes. Those who could relate were in higher educational status and who had experiences of living with diabetes patients in relations or friends circle.

Their responses on understanding on causes of diabetes were related to advices they received from their physicians and nurses. They were often advice to control their diet, to avoid eating sweets, less sugar in tea, to eat less oil, salt and other food items with high content of starch. Therefore most of them stated ‘eating too much sweet/sugar’ ‘oily food, eating fried food’ as cause of diabetes. In the study area most of the people referred to diabetes as ‘sugar disease’. This finding is in consistent with the finding of the studies on diabetes health seeking behaviour in Delhi (Goenka, 2002), USA (Johnson and Sega, 2007) and Tanzania (Nguma, 2010) where excessive sugar intake was reported by study participants as causes for development of diabetes. Biological understanding on cause of diabetes was explained by very few respondents who were in higher educational status. Stressful personal experiences were often associated with diabetes. According to patients, stressful incidences and their life events that happened before the diagnosis was of important meaning in the process of developing diabetes. This explanatory model of patients about their stressful life events and diabetes is also reported in a study among the diabetes patients of urban

poor in Chennai (Devarajan, 2013). Medelhall (2012) work on illness stories of diabetes patients also revealed the same finding as the current study. Sedentary and physical inactivity was not perceived by house wife and manual labourers as causes/risk factors of diabetes while respondents who were working in office or their work involve with sitting for long time consider physical inactivity as a cause for onset of their diabetes. This shows how the patients developed rational of why they are affecting with diabetes based on their life context, type of occupation in this case.

These findings can be put in the scenario of Kleinman's conflicting explanatory model in which patients themselves develop in response to their life circumstances to answer and to rationalise why they are having this problem. Depending on their own explanatory model they proceed to steps of self care and what they have to do to handle their health situation.

For instance, as presented in chapter 4, Mr. D, 68 years old retired army officer with 19 years of diabetes said he avoided eating sweets as he believed that his diabetes was due to his habit of over eating sweets. Some other respondents said that their job required physical activities and they do it every day. Therefore for them causes of diabetes has to something else other than physically inactive and having sedentary life.

It can be interpreted from these responses and perspectives of patients that diabetes care and treatment approach has to be more than prescribing medications and recommending to adopt a healthy life and it is necessary to develop such patients explanatory model as first step of treatment process by health care providers as suggested by Kleinman (1988, p. 122).

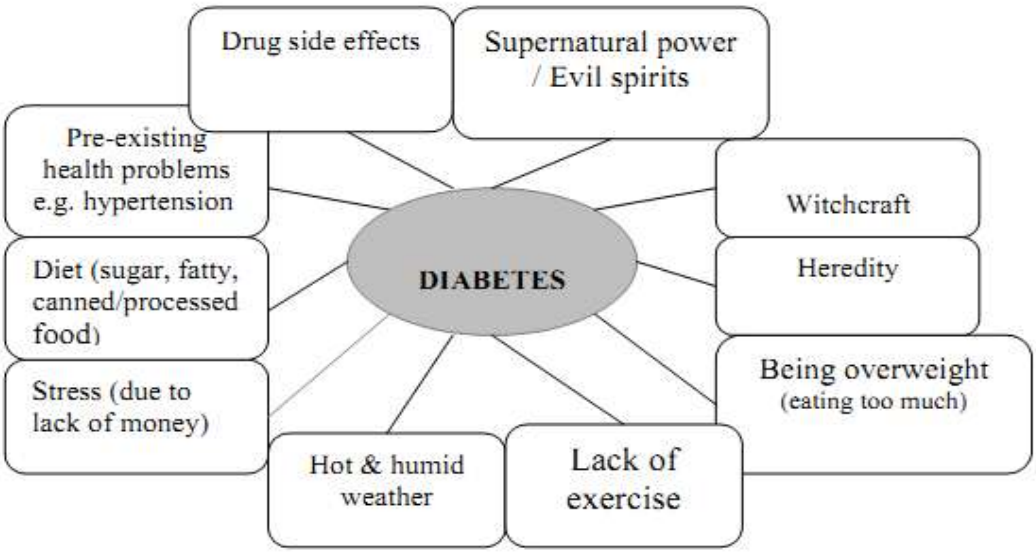
These various responses show how the understanding and perception of a particular condition is related to their socio economic position, education status, occupations and shaped by their experiences and interaction with health care providers, social network, friends, family and relatives as indicated in studies by Brown et al, 2004 and Raphael et al. 2003 on socio economic position and diabetes. A Study on knowledge on diabetes and glycemic control among patients in Bangladesh showed significant association of knowledge on diabetes with education, income, duration of illness, family history with diabetes (Islam et al. 2015). Another review of paper on perspectives on awareness and care of diabetes in India revealed that awareness about

the disease, its mode of prevention and treatment is associated with socio economic, educational status and cultural characteristics of the community (Mukherjee, 2016).

Patients' knowledge on complications of diabetes was found to be limited in the current study. Several studies conducted among diabetes patients in India (Deepa et al. 2005; Murugasan et al. 2007; Munninarayana et al. 2010) also reported lack of knowledge on complications. Most of the respondents showed uncertainty with their responses with the starting of response with 'I am not sure, there could be or I think, I heard, Doctor said'. This shows that causes and complications of diabetes were still not clear among the patients. Use of phrases such as "I guess" and "I figure" by a respondent suggests uncertainty and knowledge gaps regarding causes of diabetes and self-care management (Hernandez, 1999; Carbone et al. 2007 as cited in Nguma, 2010). Delay in diagnosis and treatment seeking may be explained by inadequate public awareness and knowledge about diabetes symptoms (Al Shafaee et al. 2008).

Multiple factors were mentioned by the respondents in this study in relation to causes, prevention and management of diabetes like eating lots of sugar, oily food, sedentary habit, physical inactivity, obesity and overweight, biological causes, hereditary, stress and super natural power/evil spirits. These factors are overlapped with the factors identified by Nguma, (2010) in her study on health seeking behaviour on diabetes among urban poor in Tanzania as shown in the figure below.

Figure 7.1 Factors associated with type II diabetes mellitus



Source: Nguma (2010), p. 221

Perception of respondents on prevention and treatment of diabetes was influenced by their understanding of causes of diabetes, cultural belief, and environmental context such as large scale exposure of food items to chemicals which is explained by 'contaminated food model'[1]. Because of their understanding on causes of diabetes due to hereditary and family history of diabetes, they felt that it cannot be prevented. Cultural and social belief in super power/black magic/ evil spirits as causes of many of the illness including diabetes attribute to their perception on non preventability of diabetes. Based on their perception and understanding on concept of diabetes treatment, their approach to diabetes care and management was different. For those who associated treatment to the concept of total cure, they were very much sure that diabetes cannot be cured. It appears that this belief is more related with the experiences of the patients and care givers than education or occupation. More than half of respondents said the diseases cannot be cure and they have to live the whole

[1] Contaminated food model: it is the increasing use of industrially processed food thereby neglecting traditional food culture. According to the research work by Nguma (2010), this change in food culture was linked to observed rise in diabetes type II in Tanzania. According to the respondents, these foods tend to contain a lot of chemicals compare to natural foods, thus exposing the individuals to the risk of diabetes and other diseases.

their life with diabetes. When probed them with the question of why do they think diabetes cannot be cured, most frequent response was ‘have you ever heard of any one cure from this illness?’ Those patients and family members who are diabetic for a year and are quite new to diabetes showed the hope that they can be cured if they take care of what they eat and take medications in time.

Perception and knowledge influences health seeking behaviour, self care and diabetes management practices Findings of this study tell us that perception and understanding of the respondents is influenced by interaction and dynamics of their surrounding context, cultural and social beliefs, their experiences, duration of illness along with socio economic and educational position of the individuals. Thus all these factors in turn relate to health seeking behaviour, self care and diabetes management practices of patients and care givers.

7.2.1.2 Health seeking behaviour, self care practices and challenges of respondents

Diseaeses are not only about physiological and pathological aspect but also its has social dimensions that it dislocates a sick individual and family in emotional, social and economic level. So knowledge and perceiveing the severity of symptoms alone is not the only factor in inlfiuencing health seeking behaviour. These above mentioned social dimensions interact with availability, accessibility and responsiveness of health care institutions influencing health seeking behaviour of a population (Baru, 2005, p. 47).

This section discusses the health seeking behaviour of respondents, reason for a particular behaviour like non adherence to treatmnet and what influences them, their concept of self care and challanges. In this study most of the repondents used private health care services for diabetes care more than govermnet services. And those who were seeking treament from govetmnet hospital were mostly belonged to lower socio economic status with less education. Those who got diagnosed in district hospital changes their consultant Physicians to those in private clinic. Preference of private clinic for seeking health care than govermnet hospital is reported by other studies (Hjelm and Atwine, 2011).

Patients visited health care providers mostly when they were not feeling well and their prescribed doses of medicine was over and when come to refill their medication. Regular follow up for weekly or monthly was found among patients who were diagnosed recently during the time of study. Studies by Kongbuha, Wallia and Kapoor (2005) in chandigarh also highlighted this followp up patterns.

From the respondents narratives on their treatment seeking process, emerging themes were stop taking medications in between and changes of consultant physicians. This behaviour of patinets is often term as 'Non adherence to treatment', 'loss to follow up' and 'doctor's shopping' by health care providers and scholars in health research.

Individual barrier such as issue of financial difficulty, structural factor of non availability of pharmacies and medicines in their accessible community, their perception on side effects of taking allopathic medicines for long terms, and their own experiences of living with diabetes were highlighted as reason for stopping medication. Interaction of these factors of distance and non availability of medicines in nearby area and social- family issues of patient's every day life was shown by narrative of Mrs. A who was not in good terms with her husband as they did not have child. Sowhen her diabetes medicine got over, neither she could ask her husband nor she colud go and buy medicine on her own as pharmacies were far from her home and also she could not leave her embroidary and stiching work because she had to finish the work order before the given dead line.

In the present study loss to follow up and changing consultant doctor was quite a common phenomena irrespective of their socio economic status. They consult different doctors as they want to get best treatment where they feel satisfy, due to unpleasant experience with a partcilur physician or clinic, as suggeted by other daibetic patients in their social network, friends, family or relatives, patients seeking for convinient and comfortable evironment for care. Over all, according to patients it was a process for looking best treateatment.

There are studies which focussed on individual self responsibility in managing diabetes care, identified individual behavioural factors as barriers to care and non adherence to treatment, asociate this behaviour with indicators for maintaining normal glucose level (Gopichandran et al. 2012; Ramachandran et al. 2008; Tharkar et al. 2011). However in this present study factors such as individual experineces of living

with diabetes like warning sign of hypolgycemia, influences of social network and evidences a person witness in the soceity along with structural factor of availability of medicine and health care services was reported. This suggest for importnace of considering larger picture rather than focussing on individual behavioural factors as reason for why patinets discontinue medicine and loss to follow up.

This finding is in accordance to finding of the study by Drummund and Manson (1990) on diabetes care which highlighted external barriers such as important role of household and larger socio-cultural context other than individual factors in non adherence to treatment (Drummund and Manson, 1990).

Process of seeking treatment from different sources, changing doctors and health care institutions is also reported in a study by Goenka (2003) among the diabetes patients of Delhi. She identified this behaviour as patinets and care givers way of seeking better treatmnet and explained this process in different 'trajectories of patient movemnets'. Loss to follow up was observed after initiating the treatment and medication which is related to belief of patients in geting cure or control nearing to cure. This is 'silent phase' which is first trajectory in treatment seeking process. After long time these patients resurfaced with symptoms of complications and they entered second trajectory 'Doctor shopping', consulting different doctors rather than the doctors who initiated treatment. This trajectory is described as 'symbolic of patients attempt to obtained better medical care and treatment'. Trajectory three is the phase where patients show the protective mechanisms in which patients develop knowledge and skiliis to adjust their treatment such as increase or decrease of dose of medication based on their diet intake and rational adaptive response to how they feel. This skill and knowledge is slowly accumulated through their experiences and environmental social network of friends and relatives, TV, radio or educatoinal materials on diabetes. Trajectory four described the phenomena of vicious cycle of hypoglycemia which patients experience due to strict adherence to medications, diets and other self care practices.

These different trajectories are observed in the treatmnet seeking and diabetes magangemnt process of respondents in this present study. Narratives shared by patients and care givers for eaxmple case of Mrs. I, who was was diagnosed with diabetes two and half years ago at district hospital, Thoubal. As there was no diabetes

specialist in this hospital she consulted one of a known edocrinologist in a private clinic in Imphal. She was on medication and follow up regularly for nearly 6-7 months and she felt much better as put by her husband ‘normal’.

This phase shows the first trajectory of health seeking behaviour ‘silent phase’ belief in getting cure or control nearing cure wich patient gets loss to follow up. Months after she started losing weight so she went to check up in their nearby private clinic and her blood glucose level was found to be very high and since thenstarted consulting the physician in this particular private clinic. This characterised second trajectory ‘Doctor shoping’ in which patients look for better care according to their perspective and context. This decision on choice of doctor or health care institute was influenced by their social network and health care services factors of distance.

Another case of Mr. R highlights third trajectory ‘protective mechanism’ of patients adaptation to diabetes management by increasing or decreasing doses of medication according to how they feel. He was suffeering from diabetes for 10 years. He accepted diabetes as part of his life that he has to manage it by his own.

Mrs A was a school teacher with 6 years of diabetes and she was 54 years old. She shared that she tried to take doctors medicines regularly and control her diet too. Sometimes she feels very tired, hungry, out of energy, tremor and shivering especially when she take many classes in a day. So she would eat a lot but sometimes she used to contol her diet as she scared about hyperglycemia. She continued to feel these symptoms of hypoglycemia most timesabout which her consultant physician never advised and did not even mentioned .

This experience is trajectory four that demonstrate vicious cycle of hypoglycemia. Health care provider did not take any notice of this hypoglyciam warning among the patients causing complications and unsuccessful management.

These different phases and process of seeking treatment show the gap in understanding and communication between care providers and patient. This finding suggested that patients behaviour of different treatment seeking process and non adherence has to be located within the specific context rather than completely focusing on individual behaviour.

Above mentioned study by Drummund and Manson (1990) conducted in Scotland also reported about behaviours to be located in their everday living experience within thier social context, their priority in daily life and their perception influencing their decision on adherence to diabetes regime within a structural context. Their decision and course of actions were justified and explained as being benefit to them in that particular time, within his or her concept of benifit. Current study also revealed that respondents decision and action of non adherence was their logical action based on their perceived benefit.

In summary, this specific context comprises of patients own perception, knowledge and skills obtained from experiences of living with diabetes, their social network, environmental context, structural issues related with health care services and provider's responsiveness. Neglecting this undertanding might lead the direction of diabetes care in opposite way instead of succesful management (Goenka, 2002).

Multiple resort pattern of seeking treatmnet which is observed in the current study that is changes of doctors, health care institutions, from govermnet to private clinic, allopathic treatmnet to tradtional healers or vice versa was explained by resasons such as unsatisfactory health care services, seraching for their comfortable environmnets to receive the best care. This explaination could be analysed based on the finding of another study conducted among urban poor in Chennai (Devarajan,2013) on social dimentions of coping among type II diabetes patiens demonstrated the concept of 'felt need' among the patients and responsiveness of health care providers as determinants of 'multiple resort pattern' in seeking health care of diabetes. Once a patient is diagnosed they seek treatment and health care srvices have to be available, affordable, accessible as well as acceptable by the patinets to fulfill their own need. After seeking care from a particular doctor or health care instititutions, if the patient experience progress in their health condition they continue to visit the same otherwise they look for other doctors or health care services like public to private or vice versa or from allopathic medicine to traditional medicine. Selection of best choice for seeking care is based on their knowledge gain from their experience or from social network including family, relatives and friends. These findings are in accordance with the current study.

This also shows the conflicting explanatory model on perspective on non adherence to treatment, self care practices, and doctor's shopping of diabetes care and management practices between the health care providers and patients and their care givers. According to providers this behaviour is considered as barriers to continuum of care and management of diabetes, they reasoned this behaviour as a result of patients and care givers ignorance, their negligence and lack of trust in their health care providers as presented in table no 5.3 in chapter 5. However from the patient's perspective this behaviour is related with their way of seeking better care. And this is influences by their experiences of interaction with health care providers, their own rational justified by their experiences and financial context.

7.2.1.3 Use of Traditional medicine in diabetes care

In north eastern part of India, studies have documented on rich traditional medicine knowledge among different ethnic communities and it has been practicing since immemorable times. Even though traditional healing practices have been declining with the availability of modern medical facilities especially in urban areas, traditional healers are still common and act as primary care providers for various illnesses (Ningombam et al. 2014; Ramashankar, Deb and Sharma, 2012, Deb et al. 2014).

The present study attempted to bring out what are the traditional healing practices diabetes patients and care givers used and what factors influence them to seek treatment from healers. Various forms of traditional healing practices in which respondents have tried are use of herbal tonics prepared by herbalists, simply using of herbs as their everyday diet in lunch or dinner without preparation and consulting practitioners, performing rituals and chanting prayers with the belief that it will chase away evil spirit which they belief to have caused diabetes and taking medicines prepared by practitioners along with prayers.

It has been reported in various studies across different countries like Uganda (Rutebemberwa et al. 2013; Atwine et al. 2015; Hajelm and Atwine, 2011), Zimbabwe (Hjelm and Mufunda, 2010), India (Modak et al. 2007), China (Jung et al. 2006), Kenya (Mwangi and Gitonga, 2014), that use of traditional medicine o r herbs for diabetes management is quite a common phenomenon.

Traditional medicine was tried or tested, with or without consulting practitioners by most of the respondents at least once. Their perception on use of herbal medicines are quite varied such as effective when used in earlier stage, relieved from the symptoms while taking herbal medicines, it has be taken without allopathic medicine to be effective, can be used as complementary to allopathic medicines especially freshly available vegetables and herbs along with their meal and want to use them but fear of worsening their conditions.

Different perceptions on use of traditional medicine reported by patients and care givers are in concurrent with the findings of a study conducted in Kenya by Mwangi and Gitonga (2014). They reported no influence of gender in use of traditional medicine however education status had influence in use or not use of traditional medicines with those in higher education using more. In the present study, patients from all the background, higher or least educated had used traditional medicines and this same finding was shown in astudy among Malaysians (Hassan et al. as cited in Hajelm and Atwine, 2011). This similar finding was also observed in the study on indigenous medicine and health care among a tribal group in Manipur, North east India reported that utilization of indigenous medicine has nothing much to do with education as the majority believe in it (Guite, 2011). However there were differences in use of different types of traditional medicines. Respondents from the higher educational status used herbs and vegetables available freshly in the garden which are supposed to be good for body as part of their regular meal. They did not particularly consult a healer for this while many of the respondents in lower educational status and illiterate reported using herbal preparations and spiritual rituals by consulting healers.

Various reasons for seeking treatment from traditional healers/herbalists were reported by respondents. One of the reasons was ‘not able to get cure by allopathic medicine and looking ways to get cure’. Many of them first sought treatment from physicians and nurses described as professional sector by Kleinman which provide bio medical health care. After trying bio medical treatment if they feel illness symptoms and signs are still there patients looked for other option that is tradition healing which lies in the sphere of ethno medicine as folk sector. Thus seeking care from this folk sector when perceiving health care as failed is in concurrent with findings from the study of health seeking behaviour in Uganda (Hajelm and Atwine,

2011) and study on complementary alternative medicine use among Indian community in South Africa (Singh, Raidoo and Harries, 2004).

Respondents were told that herbal medicine can cure diabetes and it has no side effect therefore taking herbal medicines do not cause any harm in the body. They reported that this information was often shared by their friends, relatives, family and sometimes from the healers themselves as they advertised in local news paper and TV cable channels about their medicines. This motivated and influences patients to sought herbal treatment. Thus patients and their private sphere that is popular sector influences their health seeking behaviour. This finding is in accordance with study conducted in Uganda by Rutebemberwa et al. (2013) and Kenya (Mwangi and Gitonga, 2014) on use of traditional medicine for diabetes treatment.

Perception of respondents in total cure of diabetes as their treatment goal rather than control could have been a reason to seek care for diabetes cure thereby influencing use of traditional medicines. Perceived benefit, context of social relationship that is influences from friends and family, healers themselves, their experiences (getting rid of illness signs and symptoms while taking herbal medicines), wide spread prevalent and socio cultural belief in traditional healing practices are the main reasons for using traditional medicine for diabetes care in this study. Availability of modern bio medical services and issues of affordability were not mentioned by respondents as factors influencing use of this practice. As discussed by Hjelm and Atewine (2011) in their study on diabetes health seeking behaviour, this study also contradicted the hypothesis of theoretical framework of Helman and Kleinman (Kleinman, 1990; Helman, 2007 as cited in Hjelm and Atewine, 2011) that use of folk healers in the initial stage and professional care in the later stage in persons from developing countries. In the present study health care was first sought from professional sector and when it failed they sought for alternative care from folk healer. This is explained by the fact that use of health care services is determined by interaction process of factors relating to individual, health care system and context in which it occurs (Anderson, 1995). This discussion shows that in the study, community traditional medicines are used as an alternative to allopathic medicines (using them when allopathic medicines failed to cure their illness) as well as complementary to modern treatment (used of herbs in daily meals along with modern medicines).

Opinion of health care providers on use of traditional medicine for diabetes care in this study showed mix responses. They were in favour of consuming herbs and vegetable along with daily meal but totally depending on such herbal preparations and healing prayers and rituals were considered as hindrance in diabetes treatment. Similar response was reported from the study on health seeking behaviour by Nguma (2010) in Tanzania and Korsah (2015) in Ghana.

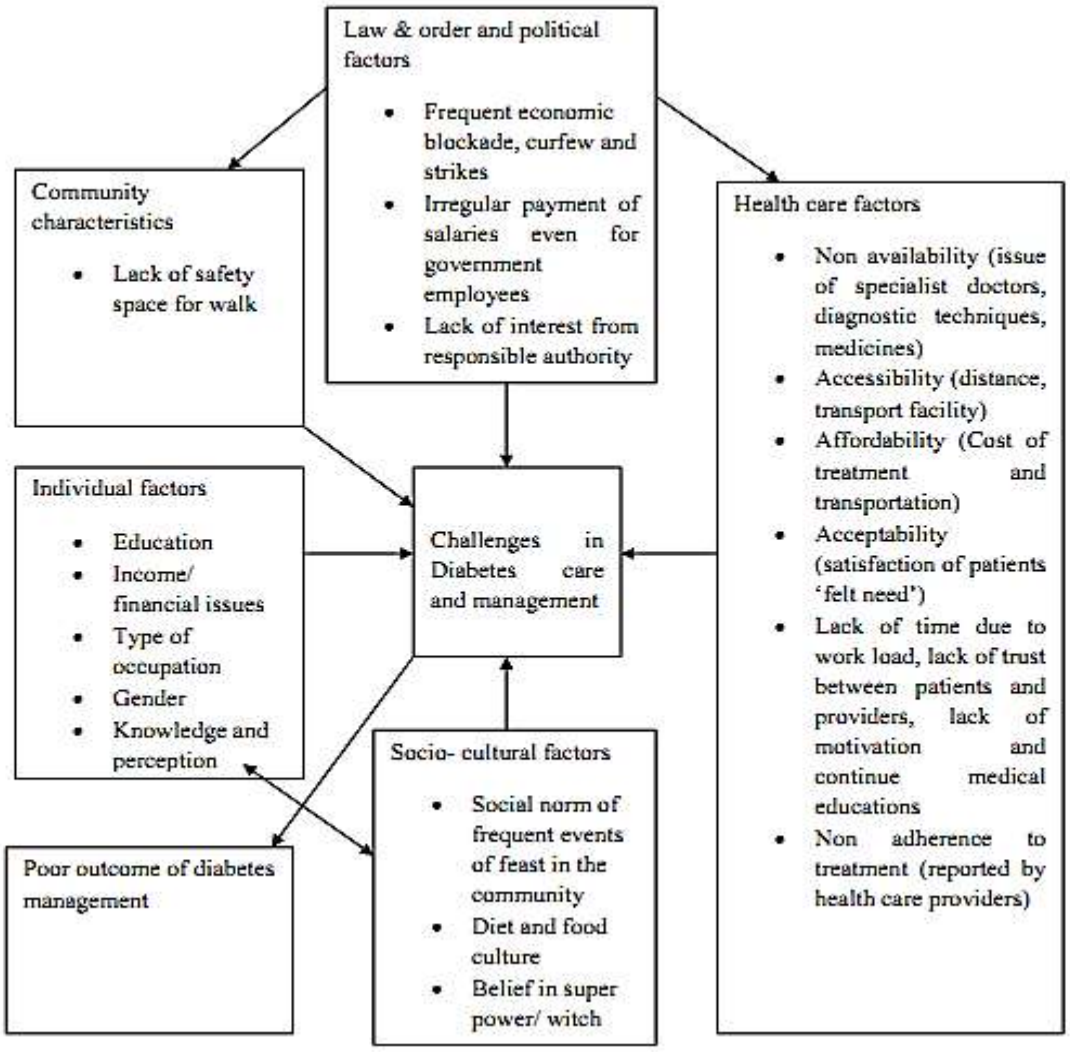
7.2.1.4 Challenges and barriers in social context of patients and their diabetes care

From this study it is observed that even though diabetes patients and care givers were aware and had knowledge on self care and diabetes management many of them were not able to follow doctor's advices. Various barriers and challenges were identified from the interviews of patients, their care givers and health care providers. This includes personal barriers such as financial issues, health care services related issues of availability, accessibility, affordability and acceptability by patients, social position, gender, cultural and social norms, law & order and political situation of the study area and environmental context. This is summarized in the following figure and all these factors interacted with each other as challenges in self care and diabetes management practices.

Several studies reported patients and providers related barriers such as lack of knowledge on diabetes management, constraints of time and facilities, providers approach to diabetes care as acute condition rather than chronic care (Pudder and Keller, 2003; Fenton et al, 2006; Hofer et al 2004 as cited in Venkataraman, Kannan and Mohan, 2009, Ramachandran et al. 2005, Wangnoo et al. 2013). A study which review the socio cultural importance in diabetes care in Myanmar identified challenges of lack of health care infra structure of well formed diabetes clinics giving comprehensive services such as retinal screening, foot care, dietary counselling requiring the need to refer patients to different specialist institutions which is a barrier to regular follow up, concentration of diabetes care facilities in tertiary hospital in urban areas. Out of pocket expenditure due to lack of health insurance system put patients and family especially from low socio economic status in financial constraints (Aye, Aung and Oo et al. 2014).

Another study conducted in Tunisia, reported that financial barrier was mostly mentioned as patient factor, poor patient compliance to diet adherence, medications, blood tests and referrals were also highlighted. According to patients and paramedical staff dietary compliance was most relevant problem whereas doctors mentioned problem of medical compliance often. Clinicians often cited poor education background of patients as hindrance in successful care. As for the health care related factors, many doctors mentioned that lack of motivation of health care provider, lack of nurses, dieticians, specialist as well as primary care doctors are barriers. Organisational factors were lack of availability of medication, HbA1c testing facility, and routine diabetes check up such as eye examination in primary

Figure 7.2 Challenges in diabetes care and management as reported by patients, care givers and health care providers



care setting (Alberti et al. 2007). These challenges are in accordance to the findings of the current study.

Above mentioned study in Myanmar relates diabetes care to diet pattern and food culture of the community in which white rice is the staple food and main diet comprising 75% of all the three meals (breakfast, lunch and dinner) (Aye, Aung and Oo et al. 2014). In this current study health care providers and some respondents pointed out this issue of high intake of white rice. Doctors suggested patients to cut down rice intake and eat roti but many respondents were not able to follow this advice as eating roti is not in the food culture of this study community.

Seeking treatment from traditional medicine practitioners particularly those practices of spiritual prayers and rituals related to super natural, witchcrafts, black magic and this social and cultural belief among the community was reported as barrier to care by health care providers. A Study in Tanzania by Nguma (2010) also reported this health seeking behaviour as barrier to successful diabetes care. Due to belief of patients and care givers, financial constraints, easily availability they sought treatment from this source first and when symptoms still persist they consult allopathic doctors. The author cited this behaviour as a reason for delay in diagnosis and treatment which is major challenge in diabetes care. In contrast to this finding, in the present study traditional medicine practice is often used as alternative source when allopathic health care failed resulting to loss of follow up which also an important challenge in diabetes care as cited by health care providers.

Lack of comprehensive health information on diabetes care was highlighted as barrier to self management in a study among the low income minority community in US (Onwudiwe et al. 2011). Similarly respondents in this study also mentioned inadequate and lack of health information as barrier to care. Many of the information booklets were in English in which illiterates and low educated respondents could not read and understand. Even among the higher educated respondents many of the contents of information were not relevant especially diet chart. Information shared by nurses and doctors were found to be confusing and unclear.

Lack of safety space and park in the community and neighbourhood was highlighted as barrier in physical activities and exercise as reported by Brown et al (2004),

Raphael et al. (2003) in their review paper on socio economic position, social determinants and diabetes.

Narratives of this study by the female respondents revealed gender as a challenge in care and management. They were dependent on their husband or children to visit doctors or buy medicines especially when clinic and pharmacies were far from their locality or for walk in early morning. Due to their gender role of taking care of their family they often put the need of family before their own need. Gender and its role in the family and society as hindrance to diabetes management were also observed in a study on diabetes coping among urban poor in Chennai (Devarajan, 2013).

A review study conducted by Raphael et al. (2004) focused on the importance of social determinants in successful diabetes management. As diabetes treatment includes changes in lifestyles, it is difficult for the patients to incorporate in their everyday life particularly for families in low income status. This study also highlighted that persistent problem of meeting food needs in poor family is more complicated when the patient is women. In food shortage situation they often prioritise their children. It indicates that personal experiences of diabetes are shaped by material context and financial constraints become a barrier to successful management. And this everyday experiences and context where patient is living profoundly influence their diabetes management.

7.2. 1.5 Coping with diabetes and impacts on life of family members

Diabetes being a chronic illness in which patient lives with it every day, coping with diabetes is also everyday task. This task is constantly changes due to factors internal as well as external to individual. Patients have to find ways to manage it and it is a full time job so coping with diabetes is also full time job (Grey, 2000).

In this study different themes on coping of respondents were emerged such as interdependence and interconnectedness of family/social network and peer support coping providing a space for sharing feelings and issues, religious, spiritual and fatalism coping, leisure to relieve stress of diabetes, medical coping by relying on doctors and their advices and self care coping strategy which is influenced by their self care health value.

This finding is similar to finding of other studies. A study conducted among aboriginal women and men with diabetes in Canada and their coping observed the same theme as this current study, social network, family support, spirituality to facilitate symbolic healing, enculturation establishing reconnection to cultural values and tradition (Iwasaki, Bartlett and O'Neil, 2005). Another study in Ghana also reported religious and cultural approach to coping with stress of diabetes, medical coping keeping regular contact with health care providers (Korsah, 2015).

Self coping strategies followed by respondents in present study also revealed the proactive managers who independently take care of themselves, practice self care and closely in touch with health care practices, passive follower with consistent in self care practices but dependent on other and family members or health care providers and lastly non conformist who do not follow self care practices and management, who are not motivated enough, denial and perceived that their health is out of their control as reported in the study by Collins et al. (2009) which characterised self coping strategies within the paradigm of self control/determination and self efficacies.

In the present study emotional coping strategy was adopted mostly by female respondents while problem solving approach was common among male. And coping strategies are mostly influenced by motivation of patients to do self care, their skills on diabetes management which have accumulated from long experiences of living with diabetes.

Family members of diabetes patients interviewed in this study reported notable burden and negative impact of having a family member with diabetes on emotional, psychological well being, stress and financial condition of family, negative impact on work or studies and leisure activities which overall affects their everyday life.

Living with a diabetes patient in a family is often described as 'living with emotional roller coaster' with full of worries related to their present as well as future life (Rintala**,** Paavilainen and Kurki, 2013). In the present study care givers reported experiencing more diabetes related distress than the patients themselves. Financial impact on family is huge leading to selling or mortgage of properties. When the head of house hold has diabetes if impact on children life is reported to be crucial as many of them drop out of school to start working and earning money.

7.2.2 Diabetes patients network: Diabetes Self Care Society, Kakching

The findings of this case study point out that patient's network can be a form of peer support. This echoes the fact that peer support has been recognized as a central strategy for successful empowerment approach to diabetes care by providing social and emotional support, and act as a link to clinical care (Kadirvelu, Sadasivan and Ng et al. 2012).

World Health Organisation has recognised peer support as a promising approach to diabetes management[2]. It reported that peer support occurs formally as part of diabetes education programs and as informally among the friends and families living with diabetes giving support and other advices. The central premise for engaging patients in their chronic disease management as peer support is that because of having same experiences and fighting to overcome same challenges, they can offer much support in term of knowledge, emotional and expertise. As daily decision on diabetes care is almost made by individual living with it without much help from health care providers, their support to other patients is of great value (Wientjens, 2008).

Recently, there is mushrooming of various online disease specific (e.g diabetes) communities, web sites, blogs and face book communities like living with diabetes in India, type I diabetes and Indian community, diabetes sweet and simple community etc. These online networks are used as a means to communicate among the people and families living with diabetes, to create more awareness and for easy connection with doctors and health professionals, members share their illness stories and seek psychological and emotional supports. Not only the care givers and patients health care professionals and pharmaceutical companies are also taking active part in such online communities. These are being used by the patients and care givers as sources of information. They often ask their doubts and other members usually share their own experiences related with the problem. While these virtual communities are accessible to only educated and internet users, there are also patients network in the community which can be a platform for social support system.

[2] www.who.int/diabetes/publications/en

Positive people's network of people living with HIV have been playing a key role in rising the profile of the AIDS, holding government and international organisations accountable and mobilizing affected communities. This is rarely the case of Non communicable diseases. Most of the international and national level NCD networks are led by health professionals, civil societies or pharmaceutical industries (NCD alliance, Young professionals' chronic disease network, Global Network for people living with NCDs) and they all work for their national government and rely on pharmaceutical companies. Though there is lack of evidence of the existence of grass root level NCD patients' network at the community, the case for an African Advocacy Network for people living with NCDs (ANPLN) showed that people living with NCDs in LMICs are silent is a myth. It further revealed that in several countries surveyed in Africa, there are 10+ grass root level PLWN groups with vocal leaders and members. However many have no funds and website. A patient led platform through which to share and amplify the voices of NCD patients are identified as the missing link for strong advocacy in the national as well as global level networks as in the case of people living with HIV/AIDS. Such patient led NCD groups can complement the work of national and global organisations. Lack of direct advocacy from people living with NCDs to their governments as well as internationally, has been identified as a critical gap in the response to NCDs to date[3].

While this side of the story focuses on the need of patients led movement and platform in larger context to make their voices heard, to gain attention from the national and international agencies related with NCDs, there are also importance of having such patient led platform as a means for peer support for self management and copping at the individual level.

Present study on diabetes self care society shows that patients network can be a platform for social support in self care and management of diabetes. These supports are in the form of emotional, informational, technical or professional support. Sharing information on physicians, which good hospital to visit, their duty time, how to take an appointment, and how much money they need to arrange were reported in the current study. Members also share their know-how on home care. They felt

[3] http://www.slideshare.net/gregpaton1/an-africa-advocacy-network-for-people-living-with-nc-ds Accessed on 12th November, 2013

comfortable with each other. Such informational support and how it can be a positive response to diabetes management have been reported in literature. It is reported that the social network of the patients provides information on the diagnosis, treatment, complications and expectation of diabetes (Winocour, 2002). Such support would give comforts and relieve stress of the patient. endures (Kadirvelu, Sadasivan and Ng et al, 2012).

Activities of this studied patient's network on organising free diabetes health camps, awareness program and check up on complications, discussion and talks on diabetes care were technical/professional support members invited from within peer group. Such social/peer network as clinical link was highlighted in the focus group discussion among the members in this present study

Various studies presented in the review of literature on social network and peer support in chapter 3 also reported support from social network and diabetes care in different forms (Jaconsen, 1986; Solomon, 2004; Peyrot et al. 2007; Schiotz et al. 2012)

Emotional support patient's gained from the network in motivating them to self manage their disease is highlighted by Jaconsen (1986) that social network offers emotional support in the form of cognitive support, involving the provision of information, knowledge and advice as well as offer material support (Jaconsen, 1986).

Various research have shown that people living with diabetes have so much to offer to each other, peer to peer interventions are in demand by patients, they are being widely used in New Zealand and appear to be of quantitative benefits in primary prevention (Simmons, 2010). It has been shown by initiatives such as United Kingdom's Expert Patient Programme that peer support can be a promising approach to increasing the quality and quantity of support (Donaldson, 2003). Oftedal et al. Reported that peer support can complement and enhance other health care services to help people follow management plans in daily life, stay motivated, and cope with the stressors of chronic disease, and at the same time stay connected to their health care providers to get the care,often in cost-effective manner (Oftedal et al. 2010). Solomon (2004) also showed that by sharing knowledge and experiences, by providing emotional as well as technical support for behaviour change peer support can be a link among the people with chronic diseases.

A study conducted in Cameroon, South Africa, Thailand and Uganda showed that effective peer support such as assistance in daily management, social and emotional support, linkage to clinical care and ongoing availability of support lead to improvement in symptom management, diet, blood pressure, body mass index and blood sugar levels (Fisher et al.2012). This study suggested that diabetes management programs using peer support can be implemented across varied cultural settings and within diverse health system (Fisher et al. 2012).

Sometimes support many not always be in a positive way. A study on social support in a by Wallhagen (1999) examined that support may be supportive or non-supportive , depending on how it is delivered, how it is viewed, and the context within which it is provided. Another work by Kahn RL (1994) revealed "support in other words, can consists of teaching, encouraging, and enabling another person, but it can also take the form of constraining, warning against, and doing for another" (Wallhagen,1999). Findings of these studies are similar with thoughts shared by some of patient's network members in the present study. They expressed the confusions over different advices and opinions among the members.

This shows the need of adequate guidance of peer members and providing them updated knowledge by health care providers. Lack of proper training, feedback, supervision and support of peer workers are identified as potential barriers in peer support especially when it is not accepted or acknowledged by the health system (Kadirvelu, Sadasivan and Ng et al. 2012). Study on analysis of failure of the UK 'Expert patient program'[4] reported the contextual problem such as lack of clinicians and health care system's interest and engagement with patients.

This is true in case of this diabetes patient's network as key members of the network shared that one of the challenges was not getting any support from heath system especially from the government sector and this limits the activities of the network.

[4] The Expert Patient Program (EPP) is an initiative of United Kingdom's (UK) National Health System (NHS) which was launched in 2002 with the aim to assist patients with their chronic disease conditions, learn better management skills and exert better control over their own health. It was adopted from the chronic disease self management program developed in the USA.

Findings on how activities were conducted by the network revealed that all the clinical related activities of the network were being supported by the pharmaceutical companies, private hospitals and diagnostic clinics associated with them. During health camps these companies sold their products such as medicines and glucose monitoring machines among the members in discounted rate. All the complicated cases identified during the camps were referred to the private clinics linked with these pharmaceutical companies. Although members of the network perceived these activities as benefits to them, it also can be highlighted from this finding that without any proper support and assistance from the government health services system, such network can be an easy channel for the entry of private health care companies into the community directly. As there is no assistance from the Government, the patients' network also depends on them to organise their health camp activities. This may paves a way for the establishment of health market in the community and this could happen in an easy way because of the current situation of health care system in India and Manipur particularly where there is a poor health care infrastructure, lack of health personnel along with growing number of private health care companies.

This process can be examined from the angle of 'Direct to Consumer advertising' concept of Rose and Novas (2005) where biomedical products are directly sold to such patients' network and group of citizenship. According to Peterson et al, 2012, virtual online communities around particular biological conditions or experiences like cystic fibrosis, haemophilia and haemochromatosis, provides a ready market place for new health care products and service in the increasing global marketplace (Peterson et al, 2012). This same idea can be applied to patients network based on community level like 'diabetes self care society' as a platform to sell biomedical products directly.

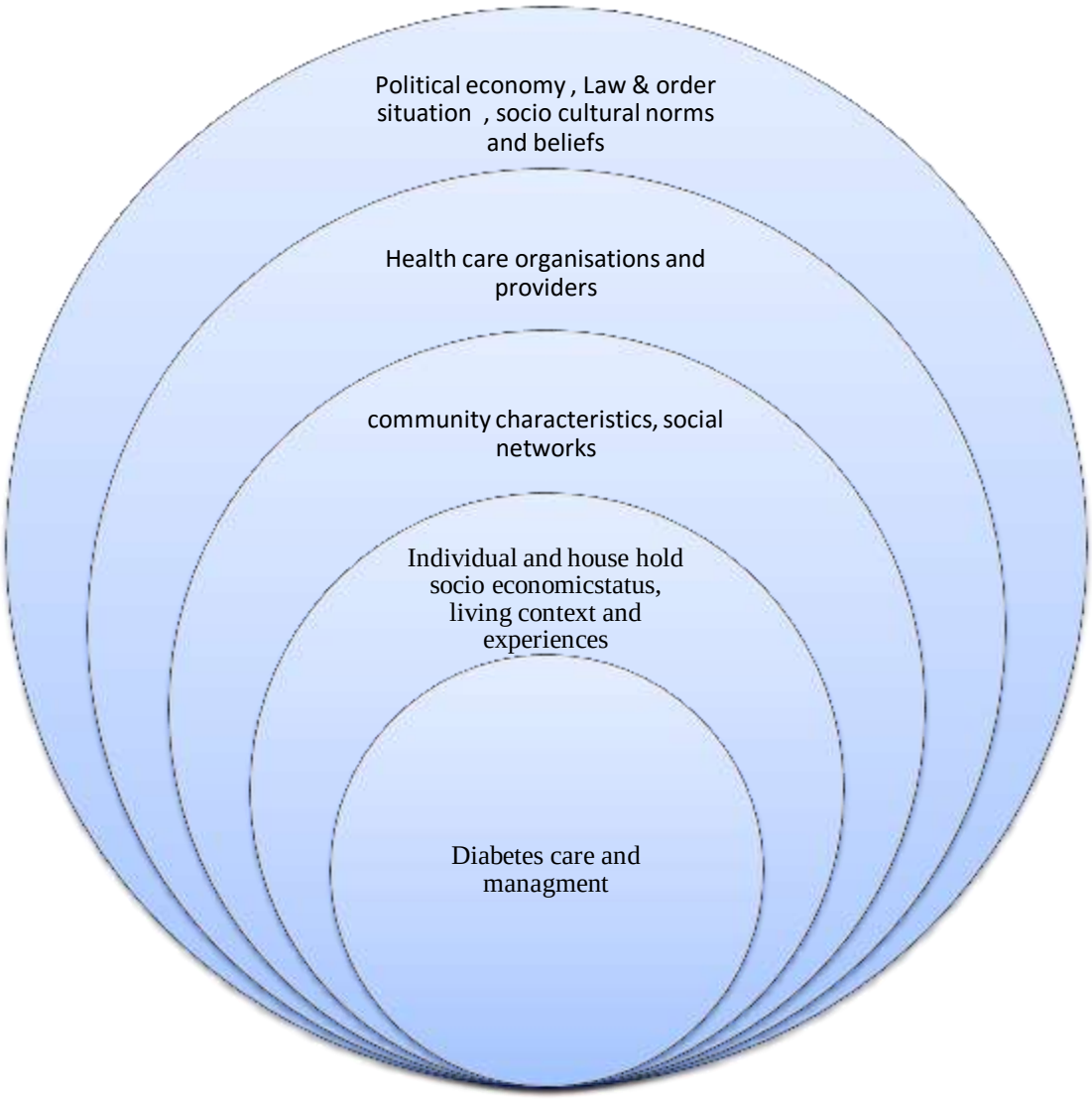
Thus from the above discussion we can see while there are usefulness of such network, there is possibility of becoming such patients' network as an easy, well established platform for entry of the private health care market. It posed the question of who is being benefited when there is such patients' network in the community. Therefore with the proper guidance and acknowledgement from health care providers and government, such patient's network could be a part of primary health care in diabetes management**.**

7.2.3 Comprehensive framework on factors related to diabetes care and management

Comprehensive framework on factors derived from this thesis which are related to successful diabetes care and management is shown in the following figure 7.3.As clearly indicated by this framework, diabetes care and management is interplay of various factors ranging from individual socio demographic and economic status, their knowledge and perception, everyday living context and experiences with diabetes which give unique rational for their action in treatment seeking, their interconnectedness and relation with family, social network and community to health care services factors of availability, accessibility, affordability and acceptability, providers responsiveness and approach to diabetes care, traditional medicine practices and larger environmental context of socio cultural norm and beliefs to political, law and order situation of the community.

Various kinds of diabetes care service provisions available in the study such as private clinic, government hospital, patient's network, NGOs, health camps organised by international civil society organisations could be used as an opportunity to develop and deliver a comprehensive diabetes care strategy in the study area.

Figure 7.3 Comprehensive framework on factors related to Diabetes care and management



7.3 Implications of the study

7.3.1 Policy level implications

Findings of this present study can provide important information on formulation of policy and program intervention on NCDs and diabetes in particular. WHO global strategy on prevention and control of NCDs in developing countries endorsed by World Health Assembly in the year 2000 aimed at mapping the emerging epidemics of NCDs and to analyse their social, economic, behavioural and political determinants with particular reference to poor and disadvantaged populations, in order to provide guidance for policy, legislative and financial measures related to the development of an environment supportive of control, to reduce the level of exposure of individuals and populations to the common risk factors for NCDs, namely tobacco consumption, unhealthy diet and physical inactivity, and their determinants; and to strengthen health care for people with non-communicable diseases by developing norms and guidelines for cost-effective interventions, with priority given to cardiovascular diseases, cancers, chronic respiratory diseases and diabetes (WHO, 2011). It suggested about risk factor prevention in integrated manners which is crucial for NCDs prevention (WHO, 2011a). According to SDH framework, these risk factors are influenced by more distal factors of socio economic, political, cultural and environmental context and these distal factors are determinants in management of NCDs (Stukler and Karen, 2012). Handling these distal factors need attentions from different sectors of the government and many areas of national policies (Stukler and Karen, 2012). In this light a high level UN meeting was held for a unified political declaration of all the member states (Chand, 2012).

In India, NPCDCS was launched in 2007 in pilot phase. This program aims to prevent and control NCDs through behaviour change, life style modifications, early detection and diagnosis and treatment, development of infrastructure and human resource capacity to provide NCDs care services. From the aims and strategies of this program we can identified the lack of policy frame work. This could be due to lack of information and advocacy to support the need for such frame work.

From this current study we learnt that when it comes to taking care of chronic disease like diabetes , changes in behaviour or lifestyle, adherence to good health seeking behaviour do not comes easily even among the patients with knowledge on diabetes.

Many factors, challenges and barriers of diabetes care were identified which are at the individual level, family, community and larger socio political context. This calls for a comprehensive framework for intervention program for NCDs management other than focusing on individual behaviours. Policy frame work for NCDs prevention and control should integrate comprehensive approach. Lack of such policy framework could be due to inadequate information and evidences which highlights comprehensive framework and advocacy to support the need for such frame work. Findings of this study could be used as information to develop a policy which takes into account of all the above mentioned interrelated factors of diabetes care and management.

WHO advocated for applying knowledge on NCDs care and management which we already have from developed countries to the development of strategies to fight against NCDs in developing countries. However studies have shown the failure of exporting such models due to difference in context (Miranda et al. 2008). In this thesis, importance of context specific at community as well as individual level in implementing policy is highlighted. For instance, this study area is completely different from other parts of India in terms of food patterns and habits and providing diabetes health education materials which is very much based on socio cultural context of mainland India like suggesting eating Roti while avoiding white rice which is the staple food of the study community do not make much sense as mentioned by many respondents. Many people affecting by diabetes belongs to lower socio economic status with varying occupations which involved everyday physical activities. As the finding of present study shows, telling them to be physically active is not really an appropriate strategy. Even though a standard guideline is needed for diabetes control and management it has be context specific depending on which section of the population they intend to serve and local socio cultural influences is need to be considered.

This study shows various individual and community related challenges such as financial issues, social position-education, income, type of occupation, gender, lived experiences, socio cultural norm. Current strategy of labelling NCDs as ‘life style diseases’ and approach to NCDs prevention and care through life style modification might not be able to bring a solution to address these challenges. There are other higher level challenges of health care organisations, overall political, law and order

situation which act as barrier. Therefore, a social determinant frame work is necessary while developing policies and strategies.

Understanding factors influencing health seeking behaviour of people with diabetes in an diverse and pluralistic health care system (i.e traditional and biomedical) is necessary to effectively advocate for a policy frame work (Shaikh & Hatcher, 2005 as cited in Nguma, 2010). In this thesis, there is very much prevalence of local traditional healing practices which patients and care givers use as an alternative source of care when the modern medication fails to control diabetes and many of them used it as complimentary along with allopathic medicines. The study community had a strong belief in this tradition where family members and social networks has major influence. Its role in diabetes care and management will continue to be significant as the use of traditional medicine is a part of their socio-cultural norm Therefore, development of a proper guideline for integrating services of traditional practitioners in the bio medical care system is necessary and it should be acknowledge in the policy framework. Diverse nature of diabetes care services available in the study area shows the possibility of integrating and mobilising different health care resources such as government, private, NGOs, community based patient's networks, health camps organisation with local resources into NCDs care. As the study also shows the danger of health care falling into the trap of market and profit making through such community based networks, a policy which provides guidelines to mobilise these resources should be consider.

7.3.2 Primary health care implications

The nature of present health care system which focuses on treatment of acute conditions is one of the challenges in NCD care. Organisations of heath care services need to redirect for chronic diseases which need long term care and slow in progression. Therefore, chronic care model based on primary health care system has developed to provide integrated response to a continuum of ill health in a community where there is lack of tertiary care facilities (Patel et al. 2011). WHO Innovative care for chronic conditions framework adapted from chronic care model in 2002 was suggested as particular relevance to India's context. This framework identifies care building blocks to redesign health care systems in low and middle income countries to deal with long term heath conditions. It emphasises patients and families self care

abilities, their interaction at the micro level; health care organisation and community and a well coordinated policy and health system environment.

WHO global health strategy in 2000 promoted primary health care system and it is one of the care models for management of people with chronic condition such as diabetes. Issues of accessibility, distance and lack of equipments which are raised during this study could be address by PHC component of NCD care model. Findings of the study highlight the importance of making the patients and care givers understand the premise that chronic diseases like diabetes cannot be cured and keeping the target of getting cure as goal of diabetes management could be a dangerous myth. This myth might distract them from step by step practices of diabetes management (Kleinman, 1988). There was lack of knowledge on diabetes. Many of the respondents highlighted the need of adequate information on diabetes. This calls for educating patients and their care givers as a component for successful diabetes management. Through primary health care facilities the patients, family members and/or social networks, can receive fundamental information for prevention, management and control of diabetes.

Based on the discussion presented earlier in this chapter, development of education modules and materials for patients, care givers and health care providers should consider conflicting explanatory model of patients and health care providers. Analysis of this model would narrow down the gap in understanding between two parties; it will help in effective communication thereby helping the health care provider in developing appropriate approach to diabetes care based on the specific context of the individuals. Likewise patients would be able to absorb the information faster as they could relate it to their everyday context.

Unlike care of acute illness, treatment of chronic conditions likes diabetes requires continuum of care and regular interaction with health care providers. Present study shows that non adherence to self care and treatment, loss to follow up and doctors shopping by patients due various reasons which includes distance factors, not satisfy with doctors treatment, influence from social networks, socio economic context such as financial, being female, family and community related issues and their own logic and rational of treatment seeking which is influenced by their experience of living with diabetes. Satisfying the felt need of the patients, learning about their lived

experiences with diabetes by giving enough time and attention could be achieved through skilled health care providers in primary health care institution where patients can easily access and approach unlike in tertiary care. This would help in reducing the communication and understanding gap.

Accessibility and distance, inadequate equipment for testing sugar level, detecting complications was highlighted as challenges. Integration of accessible and affordable diabetes care and management in the primary health care delivery services should be done along with skilled health care workers and equipped with adequate necessary material resources.

As described above in innovative chronic care model, there is a need to involve patients and families for interaction at micro level with community and health care organisations to support chronic diseases management. Findings of the study of diabetes self care society echoed this approach of peer support, social network and community based organisation in diabetes self management in form of social, emotional, technical and informational support.

Thus, a policy framework on NCDs should mobilise all the players like government, policymakers, non-governmental organizations (NGOs), community based patients networks, and other stakeholders to create an environment that will empower and encourage individuals, families, and communities to successfully managed diabetes. This calls for a multi-sectoral approach in order to address issues of diabetes care.

7.4 Conclusion and recommendation

From this thesis on qualitative study of social dynamics of diabetes care and management of patients, care givers and health care providers, several factors related to successful diabetes management were identified at the individual, community, health care organisation and socio cultural, political and economy context. It provides an insight into challenges faced by patients and care givers living with diabetes as well as providers in resource constraints environments of material deprivation, financial inadequacy, and lack of health care resources. This study also able to outlined the everyday living conditions of people with diabetes, their experiences and how such experiences influences self care and management of diabetes.

As reported in this study, large number of respondents being diagnosed about their diabetic conditions as unexpected episodes could be due to lack of knowledge on sign and symptoms on diabetes. This is the same case with knowledge on detection of diabetes complications. Due to easy access to source of health information such as news paper, health magazines, health talk in TV and radio, educated respondents were able to identify their uncomfortable signs as diabetes sooner. Rather than the knowledge and education status of respondents, explanatory model of the causes of diabetes by patients were related to their social and environmental context such as stressful life, occupations of patients (daily workers do not consider physical inactivity as a risk factor of diabetes), contaminated food model. Association of eating habit of sugar and oily food with diabetes was patients understanding of causes of diabetes which they learnt from the interaction of health care providers. Perspective on prevention and treatment was mainly influence by patient's perception of causes of diabetes, cultural belief, and environmental context such as large scale exposure of food items to chemicals. Patients belief about if diabetes can be cured or not was more related with the experiences of patients and care givers on lack of evidence of diabetes cure in their surrounding than their education or occupation status as shown by their frequent responses of 'have you ever heard of any one cure from this illness?'. This shows the lack of knowledge and the finding suggest that for developing a module or program on diabetes management education, socio cultural and environmental related factors which influence patient's perspectives should be included to deliver the health education massages which patients and care givers can relate to their everyday life context.

This study noted that knowledge and awareness of the symptoms was not the only determinant in health seeking behaviour and self care practices but individual's education, occupation, economic position and social role, responses from the health care providers in the health services system, accessibility and affordability of health services, their personal experiences which is shaped by material context of everyday life, influence of social networks, friends and families, socio-cultural norms and beliefs which are all interact with larger political, law and order situation are factors influencing their behaviour. Gender role as determinants of health seeking and care is also pointed out in this study that the multiple roles at work and home

especially in joint families, status in the family and society play an important role in health seeking and self care.

This study identified various challenges in successful diabetes management which include individuals and their everyday living context, structural, socio economic condition specific to a patient as well as over all socio economic condition of the community, cultural norm and practices, law & orders and political factors. Nature of difficulties the patients faced is also differing among patients from different socio economic status and gender. Though many literature emphasized on lack of understanding and knowledge as barrier in successful diabetes management, findings of this study showed that from the perspective of patients and care givers their social context is the major challenge. All these above mentioned factors do not act individually as barrier but they function together as a complex context in patient's life.

Conflicting explanatory model on perspective of diabetes care and management practices between the health care providers and patients was revealed by this study. Non adherence to treatment, self care practices, and doctor's shopping was one of the patient's behaviour in which care providers considered as barriers to continuum care and management of diabetes patients. However from the patient's perspective this behaviour was related with their way of seeking better care and their experiences of interaction with health care providers, their own rational justified by their experiences and financial context influenced this behaviour. This highlights the need of an approach to diabetes care where patient's perspectives and illness experience are considered in providing treatment. Chronic nature of the NCDs like diabetes calls for long term interaction with the providers for multiple times. This approach can be hindered by the problem of workload and time consumption and difficulty of regular visit to clinics due to distance. Therefore solution to this problem can be managed by strengthening primary health care delivery system for diabetes care. As observed in the study, care providers often treat diabetes patients as acute conditions and many patients prefer to go to diabetes specialist in tertiary hospital which are more expensive and far from their places. This could be managed by equipping them with proper guidance and continuous medical education on diabetes care which focus on understanding psycho-social and emotional health and illness narratives of patients

along with updating knowledge on technical and clinical aspect of diabetes management.

Continuum process of treatment seeking and dynamic nature of self care and coping strategies due to changes in everyday illness expeiences which was observed from the narratives of the reponsdents in their life experiences of living with diabetes in this current study is peculiar characteristic of chronic diseases like diabetes. This characteristic is need to be considered in developing models and strategies for continnum care of chronic illness.

Challenges of lack of health care infra structure of well formed diabetes clinics giving comprehensive services such as retinal screening, foot care, dietary counselling requiring the need to refer patients to different specialist institutions is a barrier to regular follow up, and reason for discontinuation of treatment as diabetes care facilities are concentrated in tertiary hospitals in urban areas. Developing a proper channel for reference and having a comprehensive diabetes care team in primary health care delivery services will help in effectively managing diabetes patients. This in turn will make diabetes health care services easily available, affordable and accessible to patients.

Patients across social economic status were taking multiple remedies such as combination of treatment from different system of medicine like allopathic, home remedies and traditional medicines and herbs in this study. Many of them were seeking treatment from traditional medicine practitioners as alternative to their perceived fail treatment by modern heath care as well as complimentary care to allopathic treatments. Use of this practice for illness was a very common phenomenon in the study area, Manipur. There is rich culture of belief in local health traditions among the different ethnic groups.

Traditional medicine practitioners can play key roles through care and support networks within the National Program for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke (NPDCS), contributing towards lifestyle intervention through health promotion as well as early diagnosis. Equipping them with the basic knowledge on the symptoms and complications of diabetes, and recognising their traditional knowledge and skills might be able to bring them as

front-line partner in prevention and control of diabetes. Such integrative approaches shall help strengthen diabetes management at primary healthcare levels.

Patient's network as a possible platform for social support was an important finding of the study. This shows the possible involvement of diabetes patients and community in self management strategies of NCD care. An inclusive approach to patient care can be obtained by involving patient's networks and community. People adopt various coping strategies directed at their own (perceived) circumstances. Religious faith–based organisations, social networks and other forms of social support help in many ways in coping by physical and material help and emotional support

While such organisations can be an important partner to formal structures for diabetes prevention and control, contributing towards health promotion and spread of diabetes awareness at family and community levels they might fall into the trap of profit making by these private hospitals and companies by paving a way for the establishment of market in the community. Therefore we further need to look into who is being benefited when there is such patients' network in the community.

Thus this thesis suggests for a policy framework for NCDs prevention and control which incorporates the conceptual understanding of social determinants of care and management of chronic illness such as diabetes. For the achievement of continuum of care which is necessary for successful management of chronic illness, intervention of policy and programmes on NCDs should adopt primary health care strategies. Overall this study recommends a holistic approach to NCDs care and management.

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APPENDICES

Annexure 1.1: Consent form from the respondents

I agreed to take part in this research project by Ms. Saya Okram, PhD student, Jawaharlal Nehru University, New Delhi. I have had the project explained to me. I understand that agreeing to take part means I am willing to:

- I agree to be interview by the researcher.
- I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project without being penalised or disadvantage in any way.
- I understand that any data that the student extracts from the interview for the use in reports will not, under any circumstances, contain names or identifying characteristics.
- I understand that any information I provide is confidential and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party.
- The data will be destroyed at the conclusion of the study but any unprocessed information on which the results of the study depend will be kept in secure storage.

I consent to take part in this study.

....

(Signature of respondent) (Date)

Researcher Name:…….. .. Signature……..

Date……

Annexure 1.2: Permission letter from Diabetes Self care Society

DIABETES SELF CARE SOCEITY

KAKCHING, MANIPUR

Regd. No. 35 of 2002-2003

Ms. Saya Okram, PhD student at Jawaharlal Nehru University, New Delhi has been given permission to conduct her study on 'Social Dynamics of Non Communicable Diseases: A case study of Diabetes care in Thoubal District, Manipur' among the registered members of this patient network from February, 2013 to June, 2013.

Date: 26/12/2012

N. Chaoba Singh

Secretary

Diabetes Self Care Society

Kakching, Thoubal District

Manipur- 795103

Annexure 1.3

Dr. Ksh. Manglem Singh
B. Sc. (Distn.), MBBS (Kerala), MD (Cal.)
Regd. No. 8277 (Kerala)

Supriya Diagnostic Centre
Thoubal Achouba
Near Thoubal Police Station

SUPRIYA DIAGNOSTIC CENTRE Date..... THOUBAL

Date: 23/12/2012
Age: 27 Sex: F

To whomsoever I may concern

It is to notify you that Ms. Saya Okram, PhD Student at Jawaharlal Nehru University, New Delhi has been given permission to interview and collect data from Diabetes patients of this clinic for her research work on 'Social Dynamics of Non Communicable Diseases: A case study of Diabetes care in Thoubal District, Manipur' from January, 2013 to August, 2013.

23/12/2012

(Dr. Ksh. Manglem Singh)
Supriya Diagnostic Centre
Thoubal, Manipur- 795138

অফবা চীঞাক, অফবা ঈশিং, অফবা নুংশিৎ অমসুং হকচাং শাজেল তৌবনা হকচাং ফনা থমই।

Annexure 2: Interview guidelines

Annexure 2.1

Checklist to collect information on Diabetes self care society Kakching, Thoubal district, Manipur

I. General information

- Duration of functioning
- Numbers of members registered
- Activities

II. Interview of key members of the network

1. How does this network come into existence?
2. Who were the key persons involved in the proposal of establishing this network?
3. What are the concepts behind establishing this network?
4. How the members were recruited at first?
5. What were the responses from the community?
6. How do you organise the activities? Please share you experiences. (Difficulties, barriers, Financial as well as community support)
7. Do you get any kind of assistance from the government or any other health care facilities?
8. Do you think this network's activities are helping the diabetes patients in your community and how?
9. Pleases share your opinion on engaging such network in diabetes care.

III. Focus group discussions guideline

1. How do you come to know about this network?
2. Why did you become a member?
3. What are the activities you have participated?
4. What do you think about these activities (benefits, negative impacts)
5. Pleases share your opinion on engaging such network in diabetes care.

Annexure 2.2

Interview schedules for diabetes patients in Thoubal district, Manipur

Date of interview:

I. Personal information

Name:

Sex:

Age:

Marital status:

Religion:

Caste:

Educational status:

Occupation:

Monthly income:

I. Details of Household members

Household members and relationship to the respondent	Age	Educational status	Occupation	Monthly income

II. Clinical and treatment history of the patient

1. Date of diagnosis (Duration)/ Age at Diagnosis_____
2. Type of Diabetes_____
3. What were the ailments and complaints that lead to diagnosis?
4. Whom and where did you visit first with your complaints?
5. What was the type of treatment following diagnosis? Oral/ Insulin therapy/herbal/traditional medicines?
6. Other diabetes patients in your family?

III. Knowledge and perceptions about type II diabetes

1. What do you know about diabetes and how did you feel before you were diagnosed? (Probing on signs and symptoms experienced by patients before diagnosis).
2. Why do you think you had these discomforts? (probing on the relation patients put with their life event and development of diabetes)
3. What are the major symptoms and signs of type II diabetes? Did you experience these symptoms before you were diagnosed with this disease?
4. What is your opinion on what causes type II diabetes?
    1. Is type II diabetes preventable, treatable and curable? What is the reason for your answer?
    2. What are the complications one is likely to get if he/she is not treated in time?

IV. Information related to type II diabetes care and management practices by the patients

1. Current treatment/ Type of regiments:
    - Oral
    - Insulin
    - Oral and Insulin

2. Current associated problems and complications
    - Retinopathy
    - Nephropathy
    - Neuropathy
    - Foot ulcers
    - Others (heart, limbs, BP, Stroke, hypoglycaemia)

3. Which hospital do you go for treatment? Govt./ Private clinic/ Others, Why?
4. How far is it from your home? How do you go there?
5. Are you satisfied with the services of your consult doctor? If so, how?
6. How often do you monitor your blood sugar level and blood pressure? (How often do you go for check up? (monthly / weekly)
7. Do you regularly take your medication or only when you are not feeling well? If not. Why?
8. Have you been consulting the same doctor? If no, why?
9. Any changes in course of treatment since diagnosis?
10. What kind of diabetes management advices were given to you by your consult doctor?
11. What is your opinion about the treatment and advices of your consult doctors?
12. What do you think about self management of diabetes?
13. What, according to you is the best for management of diabetes?
14. Do you also consult doctors other than the allopathic medicine?
15. Any other comments about your own management and care practices other than doctor's medications like food habit and exercise...

V. Probing on experience of living with diabetes, impact on life, difficulties and family support

1. Please share about your diabetes condition and your daily routine.
2. What was your reaction when you first found out your diabetes condition?
3. How does having diabetes impact your life?
4. Is there any change in your job due to diabetes (ability to work / absenteeism)?

5. Does any member of the family need to work to compensate the monthly income of the family since diagnosed?
6. What support do you get from your family? (Probe: Who would you say provides most of your care/support and what are the tasks that this caregiver carries out for you?)
7. Do you face any problem while accessing health care services (while going to clinic for treatment, any difficulties in following doctor's advices or in accessing your medication, probing on availability/ affordability of medicines-insulin as well as oral medications)
8. How do you manage/cope when such situations come up? (How have you been addressing these challenges?)
9. In your opinion what should be done to help people with diabetes attend the health care facility as required? (Probe: What needs to be done to empower patient caregivers in taking care of people with diabetes at the household level?)
10. Are there any questions you would like to ask me?

Annexure 2.3: **Interview schedule for care givers and family members**

1. What do you know about diabetes?
2. From where do you get information regarding diabetes? Do you get any advices from the consult doctors about the management and care of diabetes patients?
3. Please share your experiences about having a diabetes patient at your family.
4. Are there any difficulties in running the household? If yes, please explain
5. How do you cope to such difficulties?
6. Any other comments

Annexure 2.4: Interview Schedule for health care providers of Thoubal District, Manipur

Date of Interview:

Name:

Name of the Health facility:

Qualification:

I. General information

1. How long have you been working in this health facility?
2. Which are the various medical problems that patients come to you?
3. What is the approximate number of patient seen by you in a day?
4. Please share the problems/constraints faced by you during practice.

II. Diabetes: treatment and management

1. On average, how many diabetes patients come to you? (week/month)
2. Do you remember any new case of diabetes in the last week? (month)
3. From your experience, please tell me how do you suspect diabetes in your patients/ When do you ask for blood sugar check up? (Diagnostic criteria).
4. In your practice, have you encountered any complications of diabetes? If yes, which ones?
5. Do you need to refer your diabetes patients? Where do you usually refer them?
6. Please describe the availability of diabetes medications and related services in this clinic.
7. What are the problems faced by you in effective diabetes management of your patients?
8. How would you describe the patients' attendance at this clinic? (Probe Q: How would you describe the patients' overall adherence to their prescribed treatment programmes?)

9. Another thing that doctors share with me is that switching of doctors is common, that is ‘doctor shopping’, please share your experience?
10. What problems do you think most of your patients have in managing their disease?
11. What is your opinion regarding self care practices of your patients for example diet control and physical activities?
12. What are the existing opportunities outside the biomedical health system which can be used to improve early health-seeking behaviour for diabetes treatment? (Probe: What are the weaknesses in the existing health care system, which are barriers for accessing early diagnosis and treatment of diabetes?)
13. Many patients are also looking for the alternative options other than the allopathic medicine like homeopathic, Ayurvedic and other local traditional and herbal products. What is your opinion?
14. In your opinion, what do you think health care providers can do to help people with diabetes adhere better to their treatment programme? (Probe: What can be done to help people with diabetes to attend the diabetes clinic earlier? What do you think needs to be done in empowering people with diabetes to manage their disease condition?)

Appendix 3: Socio demographic details of respondents (Patients)

Variables	Private clinic (20)	District Hospital (14)	Patients' network (20)	Total (54)
Age				
30-40	4	3	5	12
40-50	5	4	5	14
50-60	6	5	5	16
60-Above	5	2	5	12
Sex				
Male	5	8	5	18
Female	5	6	5	16
Education				
Illiterate	5	7	3	15
Primary	4	5	5	14
Secondary	6	2	5	13
Bachelor-Above	5	None	7	12
Occupation				
Employee	5	None	8	13
Self/ small business	5	3	6	14
Daily wage earner	5	7	3	15
Not earning	5	4	3	12
Income (INR)				
Less than 10000	None	8	4	12
10000-20000	6	6	6	18
20000-30000	7	None	5	12
30000-Above	5	None	5	10