

**Social Dimensions of Coping with Type II Diabetes: Study of
Select Villages in Kanchipuram District, Tamil Nadu**

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

DOCTOR OF PHILOSOPHY

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DECLARATION



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DECLARATION

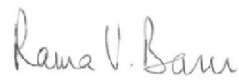
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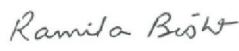
I hereby declare that this thesis entitled "SOCIAL DIMENSIONS OF COPING WITH TYPE II DIABETES: STUDY OF SELECT VILLAGES IN KANCHIPURAM DISTRICT, TAMIL NADU", submitted to Jawaharlal Nehru University for the degree of Doctor of Philosophy is my original work. This thesis has not been previously submitted for the award of any other degree of this or any other university.


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CERTIFICATE

We recommend that the thesis be placed before the examiners for evaluation and consideration of the award of Degree of Doctor of Philosophy.


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INTRODUCTION

Type II diabetes, the most common type of diabetes, is increasing worldwide that affects both the rich as well as the poor. It imposes several challenges to the affected individuals in terms of bodily signs and symptoms, social and economic burden in terms of changes in social role, everyday life adjustment and treatment expenses. It also affects nations' economy, as onset and disability due to diabetes affects larger number of people in the productive age group. It requires chronic care and regular monitoring. The lack of appropriate care leads to uncontrolled sugar and impairment of other body parts like eyes, kidney, foot, heart. There are national and international programmes which target the prevention and control of diabetes. In India, the National Programme such as Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke has given a way for people to undergo diabetes screening and treatment. But handling everyday needs of diabetes and broadly coping with it continues to remain a challenge.

A fair amount of evidence shows the positive association between treatment adherence and good glycaemic control. Majority of the studies used the quantitative methods and showed the persons with diabetes who adhered to the treatment advice were having better health condition. Comparatively high proportion of people who were not compliant to the prescribed regimen had poor health outcomes. Here the process is not captured in a comprehensive way as it gives the outcome indicators such as high level of blood glucose, more number of complications, rising illness expenditure among people who are non-compliant. Hence it can also be said that the process in accessing diabetes care are reduced into number of variables or factors in determining and predicting better health and poor health.

The better predictor of glycaemic control also lies in the level of compliance to balanced diet, regular exercise, follow up of medication and monitoring of blood glucose. Hence it is known that the importance given to self-care behaviours, which broadly constitute individual lifestyle modification, informed by bio-medical approach. Very few studies have tried to capture the process in attaining the glycaemic control which involves interaction between the individual and the social context, which is complex. With the notion that diabetes is a multi-factorial disorder, it can be interpreted that there is a multiple and complex interaction of the biological, psychological and social process in both causation and coping with diabetes.

From a Life Course perspective, it is shown that socio-economic position at various stages of life could influence cardiovascular health. For example, parental socio-economic position has an effect on intrauterine condition, growing environment of the children and behaviours, working condition and related stress which may determine accumulation and distribution of exposures to risks of diabetes and cardiovascular diseases. So, it is difficult to have a broader understanding on the issue when the individuals are studied in isolation from their social context.

Recent literature country's disease burden (India State level Disease Burden Collaborators, 2017) shown the increasing trend of non-communicable diseases and also unsettled issue of communicable disease. India is also facing the issue of dual burden. Literature has shown that the incidence of diabetes is rapid in urban areas and there is also gradual increase of diabetics in rural areas too (Anjana et al., 2011; 2017). With the available evidence it is observed that people in rural areas are affected more in terms of poorly controlled sugar, onset of complications, late screening for complications compared to their urban counterparts (Kapur A, 2004, Vijay V et al., 2006, Ramachandran A et al, 2008). The attributed reasons were poor economic status, employment, family level priorities, transport and place of residence (CODI, 2000; Fano V et al., 2012, Drummond N and Mason, 1990) and which denotes more of social and material deprivations and which are the important determinants in coping with everyday management of diabetes (Raphael D., 2003). Hence the literature has shown that one or the few aspects of coping and left out the other aspects, which needs to be added in capturing the comprehensive picture of coping with diabetes.

My earlier study on "Social Dimensions of Coping with Type II Diabetes: An Exploratory study in Chennai" (Devarajan A, 2013; 2016) has provided insights into how individuals with diabetes perceive their illness and how they seek treatment based on the experiences of symptoms. It has also given a broader understanding on how an individual respond to the severity of the symptoms and also the responsiveness of the health care services, which influenced multiple resort pattern. The wider variation in everyday coping is also found across class and gender. Hence this actually provoked us to think about the people involved in agriculture in rural areas handle this chronic disease as it's an everyday need is a challenging task for poor. Diabetes itself is an idiom of expression for poor Mexican Americans through which they brought out their everyday stressors and social sufferings (Mendenhall E, 2010). It is also learnt that perspectives from the health care providers are also equally important to

understand the interactions of individuals with health care services and also the responsiveness of the health services system in the provision of diabetes care.

Hence this current research has employed an interdisciplinary inquiry to understand coping with diabetes at multiple levels such as individual's everyday experience, individual's interaction with family members and with health services in terms of accessing diabetes care.

Hence with this comprehensive understanding of the research problem, this research is carried out in the rural areas of Kanchipuram district, Tamil Nadu and the report is compiled as a thesis with the following chapters

1. An introduction is given in order to introduce the background of the research and this section also includes an overview of all the chapters of the research.
2. **Chapter 1** titled as **Review of Literature** which gives an understanding of the global burden of diabetes, further India's situation, then the prevalence of complications of diabetes and other co-morbid conditions and further this chapter enters into how people cope with diabetes, the Social and cultural aspects of coping with diabetes and the approaches in studying the coping with type II diabetes.
3. **Chapter 2** titled as **Research Methodology** has summarised the approaches in studying coping with diabetes, then it has brought out the gaps in literature and approaches in studying the coping and getting into the concept of coping and further conceptualization using an interdisciplinary approach. Later the method and design worked out in conducting the study importantly the selection of the study villages and the participants has been explained and an overview of data analysis is also given.
4. **Chapter 3** titled "**Socio-Economic Characteristics, Disease and Treatment profile of the study participants**", which first gives an overview of the socio-economic profile of the study participants, then the prevalence of diabetes among the participants across gender, caste and class. Similarly, the prevalence of complications and co-morbid conditions is described and discussed. Then the focus is given on how the participants are selected purposively for the in-depth study using the information on the first phase survey. The list of the participants who participated is also represented in order to have an overview of their socio-economic, Disease and treatment profile.

5. **Chapter 4** which is on “**Experience of symptoms and process of treatment seeking behaviour**” will show how the individuals have perceived, experienced the symptoms and further the process of treatment seeking. This is a compilation of individual experiences in how the individuals are dealing with detection of diabetes and further treatment. This furthers how individuals associate their onset of diabetes to other social conditions and sufferings which goes beyond the clinical understanding of diabetes.
6. **Chapter 5** explains “**Everyday Coping with diabetes**” which focused mainly on the daily routine of the participants importantly their social roles and responsibilities and how it gets interacted in dealing with the everyday demands of diabetes and how far the needs are satisfied and the variation pattern in coping with diabetes across gender, caste and class is highlighted.
7. **Chapter 6** gives a broader understanding on the **individual’s interactions with health care services** in receiving diabetes care, and similarly the responsiveness of the health care services importantly the factors which facilitates or constraints the provision of diabetes care.
8. Finally, in the **chapter 7** the results are discussed using the analytical framework and concluded.

CHAPTER I
REVIEW OF LITERATURE

2. Burden and Impact of Type II Diabetes - an Understanding of the Problem

2.1. Prevalence of Diabetes

Non - Communicable Diseases (NCDs) are found to be the important contributors for morbidity as well as mortality globally. It is estimated that 6 out of 10 deaths occur due to NCDs importantly cardiovascular diseases, cancers, diabetes and other diseases like chronic respiratory diseases. The deaths due to NCDs are more than the deaths due to communicable diseases. The deaths due to non-communicable diseases occur in the productive age group (30-70 years). Moreover, 72.5% of deaths are due to Non-Communicable Diseases and Injuries across the states of Goa, Kerala, Punjab and Tamil Nadu have reached the high epidemiological transition level. Type 2 diabetes (hereafter diabetes) is one of the major disorders among NCDs (United Nations Development Programme (UNDP), 2013; India State level Disease Burden Collaborators, 2017). The incidence of diabetes is increasing in low and middle-income countries compared to developed countries. Currently there are 425 million people with diabetes (221 million males Vs. 203.9 million females) worldwide and among them 80% living in low and middle-income countries. This numbers might increase to 629 million in 2045 (International Diabetes Federation (IDF), 2017).

The countries such as China, India and USA are holding the top 3 positions in the prevalence of diabetes since 1980. The increase in the prevalence is observed in both China and India. Although USA remains in the same position the number of persons with diabetes were not increased during 1980-2014 (NCD Risk Factor Collaboration (NCD RiskC), 2016). Earlier India had 64.5 million people, it was estimated that 34.5 million were living in rural settings and 30.5 million were living in urban areas (IDF, 2013). The present scenario shows that next to China, the 'diabetic capital' of the world (114.4 million), India has 72.9 million people with diabetes. Out of 72.9 million, 37.4 million people are living in the rural areas and 35.5 million are living in the urban areas. Whereas the global picture shows that there are 146 million people living in rural areas and 279 million people with diabetes are living in urban areas (IDF, 2017).

A systematic review of prevalence studies in rural areas from 1990 to 2012 had shown global rural prevalence of 6.0%. This study also reported that there was a gradual increase in the prevalence in rural areas of developed as well as developing countries (Zabatien A, 2014). Cross sectional studies conducted in India since 1970s showing the rural-urban difference i.e. the prevalence of 1:2 ratio in rural and urban areas respectively. The increasing trend is also

observed gradually in both the areas (Mohan 2006; 2007 and Anjana et al, 2011). The reasons attributed to this include the demographic and nutrition transition. It is also argued that this increasing prevalence is due to urbanization, westernization and adopting unhealthy life style such as unbalanced diet, physical inactivity, smoking and alcohol intake (Mohan 2007).

National surveillance was done by Indian Council for Medical Research (ICMR) between 2008 and 2010 across three major states and one Union Territory that included Tamil Nadu, Maharashtra, Jharkhand and Chandigarh. It showed the diabetes prevalence of 13.7%, 10.9%, 13.5%, 14.2% in the urban areas and 7.8%, 6.5%, 3% in the rural areas of these states respectively (Anjana et al., 2011). A review study by Misra et al in 2011 showed the prevalence of diabetes in rural India ranging from 2.1% to 13.2%). The recent Indian Council for medical Research India Diabetes (ICMR INDIAB) (Anjana et al., 2017) study in 15 other states has revealed again that diabetes is more prevalent in urban areas than rural areas. The authors also have pointed out that around one-third of Indian population live in the rural areas and hence a little raise in diabetes prevalence in the rural areas will decode into several millions of individuals.

2.2. Prevalence of Complications and Co-morbid conditions

Nearly one third of the newly diagnosed type II diabetes subjects had some form of micro vascular complication. The neuropathy and nephropathy were more prevalent (10.7%) than retinopathy (4.8%) (Rajiv R et al, 2012). The complications are increasing with increase in age and duration of diabetes. Diabetes is no longer considered as a disease of rich as its prevalence is gradually increasing among the middle and working classes (Kapur A, 2004).

Diabetes creates social and economic challenges to not only the people affected with the disease but also their families, communities and society at large. It also affects the nations' economy since around 50% of them are in the productive age group (IDF, 2017). When we look into the occurrence and risk of complications, there are number of socio-economic factors play a significant role in delaying diagnosis and treatment of diabetes. They are mainly area of residence, housing tenure, education, employment and income and socio-economic status which further contribute to delayed or irregular treatment and further the onset of complications (Cost of Diabetes in India (CODI), 2000; Kapur A, 2004; Fano V et al., 2012). Few population-based studies were conducted on the prevalence of complications. A third of the people in urban areas who were newly diagnosed with diabetes had micro-vascular complications. (Rajiv R et al, 2012).

Another study reported a prevalence of 30% of Coronary Heart Disease (CHD) and 60% of Neuropathy among diabetes patients in urban areas (Ramachandran A, 2002). A study conducted in rural Goa had shown 32% (CHD), Neuropathy (60%) and retinopathy (20%) respectively (Nafisa V et al, 2011). People who were residing in semi-urban or rural areas were diagnosed with the disease four years later than their urban counterparts. It was also observed that those who are employed in other sectors had fewer complications than the unemployed and agricultural labourers. Among people with similar diabetes duration, majority from high socio-economic group had fewer complications or were free of complications. Despite lesser duration of diabetes, people in rural areas had shown more presence of complications than their urban counterparts (Kapur A 2004; 2007).

A study conducted at the foot clinic among urban (n=1377) and rural (n=1265) diabetic patients having the similar duration of diabetes and peripheral vascular diseases. The mean age is found to be high among urban people than the rural people. Similarly, the rate of foot infection and amputation, recurrence of infection is found to be high among rural diabetes patients than their urban counterparts (Vijay et al., 2006). Prolonged delay in diagnosis, irregular treatment, poor living conditions, lack of family cooperation, dependency, priority to other commitments in the family, loss of work and wage due to hospital visit were attributed as reasons for not given attention to their disease condition at the right time (Vijay V et al., 2006; Srinivas et al, 2002).

The cost of illness was higher among the people belonging to the lower socio-economic groups and also increases with the duration and number of complications (Ramachandran A 2007; Tharkar S et al., 2010). Ramachandrans' (2007) study had shown that urban people had spent more than rural population on diabetes whereas another study had shown that diabetic people in rural areas spent more on their treatment than urban counterparts mainly the cost towards hospitalization (Chronic Care Foundation, 2010).

2.2.1. Diabetes and Hypertension

The presence of co-morbid condition such as hypertension would increase the risk for development of diabetic complications such as kidney diseases, retinopathy, cardio-vascular diseases (IDF, 2017). Hence it is also important to monitor the diabetes patients for hypertension. In India, the prevalence of hypertension (without diabetes) is ranging 17% to

28%. The rural-urban difference in hypertension is less, 14.8 to 27.6% in rural areas and 21.4% to 33.8% in urban areas (Kaur P et al., 2012; Anchala R et al., 2014 and Bhadoria AS et al., 2014). The prevalence of hypertension among people with diabetes is higher than people without diabetes.

2.2.2. Diabetes and Depression

The conditions such as depression and anxiety are also required to care as it affects the higher proportion of people with type II diabetes. A study by Weaver LJ and Madhu SV (2015) have reported high prevalence of anxiety (40%) among people whose duration of diabetes is less than 2 years whereas it is 23% when the duration of diabetes is more than 2 years. The same study sample has shown 18% of severe level of depression symptoms. People with complications have reported high level of depression compared to people without diabetic complications (Poongothai et al., 2011). Another study (Joseph N et al., 2013) reported about 30% of diabetics with moderate level of depression compared 14.3% has severe depression. A systematic review (Subrata N et al., 2017) of 41 studies in India has shown 8% to 84% of depression among people with type II diabetes. Older age, female gender, low socio-economic status, unskilled/retired employment status, low socio-economic status and presence of complications/co-morbid conditions, being on insulin are the factors which have shown significant association with depression (Subrata N et al., 2017; Joseph N et al., 2013).

2.2.3. Diabetes and Tuberculosis (TB)

Our country is facing the dual burden of diabetes as well as Tuberculosis. The presence of TB among diabetics or vice versa is a challenging combination of diseases. It is found that 2.3 million people affected with TB are living in India out of 9.0 million people with TB incidence estimated globally. Studies conducted in South India have shown higher prevalence (25%) of diabetes among people with tuberculosis (Vijay V et al., 2012; Balakrishnan S et al., 2012). While the study conducted in North India has shown 15.4% prevalence of diabetes among people with tuberculosis (Agarwal AK., 2017). The presence of diabetes with TB will delay the cure of the disease and similarly the presence of TB in diabetics will have a negative influence on hyperglycaemia and sugar control (Vijay V et al., 2015).

2.3. Government Initiatives in the Prevention and Control of Diabetes

Since Independence, India has made several efforts for improving the health status of the population by building its health and health services system. There were several shifts in policy for improving the health status of the country. It includes the strategies focused on

maternal and neo-natal care, nutritional problems, and communicable diseases to non-communicable diseases. The reduction in maternal and infant mortality rate that was unable to achieve the Millennium Development Goals (MDG) target, recurrence of diseases such as malaria and other communicable diseases, poor nutritional status among children continue to remain as challenges in achieving health improvements in India (Paul VK, 2011). Apart from these challenges the increasing proportion of NCDs puts enormous burden on the health service system (Guptae MD, 2001; Patel V t al., 2011).

In order to address these challenges India would require a strong public health system with adequate funding. However, the experience of the last three decades of Health Sector Reform that has led to increased commercialisation of health and health services. The health strategies then were much influenced by the donors (funding), health care reforms which changed the comprehensive approach to very narrow techno-centric, vertical programmes during 1980s and 1990s (Baru RV 1998; Qadeer I, 2000).

Current status on disease burden in India has highlighted that country experiences at varied stages of epidemiological transition resulting in variation in disease burden across states (India State level Disease Burden Collaborators, 2017). Hence with a huge burden of NCDs, we need to look into the government initiatives for the prevention and control of NCDs.

2.3.1. Initiatives for addressing NCDs

This increasing burden has brought responses from various national and international agencies, which has led to the formulation of preventive and control programmes that includes standard treatment guidelines. During 1987, the government initiated National programme for the prevention and control of diabetes. But due to lack of funds, the programme was stopped after attempting pilots in few districts. Later in 2004 there were efforts for surveillance of risk factors but did not emphasize on intervention. Then in 2008 government initiated the pilot phase of National Programme for Prevention and Control of Diabetes, Cardiovascular Diseases and Stroke (NPPCDCS). Then the efforts were continued through 11th and 12th five-year plans to upscale the programme in all the districts (Association of Physicians of India (API), 2002& 2007; IDF, 2005; ICMR, 2005; American Diabetes Association (ADA), 2011; Ministry of Health and Family Welfare (MoH&FW), 2012; Pandav et al., 2010).

Presently, the National Health Policy 2017 has proposed to raise the public health spending to 2.5% of Gross Domestic Product (GDP). But the health budget still stagnated at 1.2%¹². Policies also propose to ensure providing comprehensive primary health care through the 'Health and Wellness Centres'. This includes geriatric health care, palliative care and rehabilitative care services. This also aims to allocate up to two-thirds of resources to primary care. It has also envisioned providing most of the secondary care at the district hospital and which now provided at a medical college hospital. Policy also highlighted the need for scaling up activities of the prevention and control of NCDs, the national programme NCPDCS (National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke) in all the districts of the country. The current approach to deal with NCDs like diabetes has focused on the individual's life style such promoting healthy lifestyle such as healthy diet (includes consumption of fruits and vegetables), practice of yoga. It also mentioned the systematic screening of diabetes among people with tuberculosis.

mDiabetes, a Mobile Health Initiative was also launched by the Ministry of Health and Family Welfare (MoHFW) in collaboration with the WHO Country Office for India for the prevention and care of diabetes. This contributes to improve awareness about diabetes, promote healthy lifestyle through national Health Portal. Using the mobile technologies, the government has tried to intervene in the prevention and control of diabetes³.

The interventions for NCDs were initiated much in advance in the states like Tamil Nadu⁴ and hence it is reviewed to have a broader understanding on the policy efforts and strategies in the prevention and control of diabetes.

1.3.2. Interventions for NCDs in a high disease burden State: Tamil Nadu

The state's responses in the prevention and control of diabetes is as follows

- a. Prevention of Cardio-vascular Diseases and Diabetes: Combating Non-Communicable Diseases is one of the important objectives of Tamil Nadu Health Systems Project. As a part of it, a pilot survey was conducted in 2007-2008 four districts Sivaganagai, Virudhu Nagar, Theni and Villupuram, assessed the level of awareness about risk

¹Available at <http://www.cbgaindia.org/wp-content/uploads/2017/10/Health-Sector-in-India-Need-for-Further-Strengthening.pdf> accessed online on 17.07.2018

²Available at <http://www.cbgaindia.org/wp-content/uploads/2018/02/Of-Hits-and-Misses-An-Analysis-of-Union-Budget-2018-19-2.pdf> accessed online on 17.07.2018

³Available at <http://www.mdiabetes.nhp.gov.in/> accessed online on 17.06.2018

⁴ Available at <http://www.nrhmtn.gov.in/npcdcs.html> accessed online on 15.07.2018

factors regarding Cardiovascular Diseases and estimated the burden of diabetes, hypertension and Coronary Heart Disease. The estimates then had shown that 20% of the adults aged above 30 years had hypertension, 30% were diabetic and 10% had heart disease⁵.

- b. Scaled up this model to other districts in a phased manner during 2012-2103 and later.
- c. Spread of NCD clinics in PHCs and GH in every block of the districts through ‘Nalamana Tamizhagam’ (opportunistic screening). Later the same continued with ‘Amma ArogyaThittam’ through which the (target) screening for NCDs (mainly hypertension and diabetes, cervical cancer (female) taking place continuously.
- d. Prescribe medicines such as anti-hypertensive agents and anti-hypoglycaemic agents.
- e. Referral to secondary/ tertiary health facilities to handle complications /abnormal condition of sugar.

The programme is institutionalized and implemented by NCD cell in the district health society of each district.

In addition to these programmes, there are many projects, clinical trials and community-based projects in the form of intervention (trials) conducted in India. Most of them are collaborative projects and funded by World Diabetes Federation. There is a total of 316 trials in India and more than one-third of the total trials in India are conducted for diabetes. Similarly, more than half of the projects in South East Asian Region are in India, funded by World Diabetes Federation. These projects mainly focused on building awareness, mass screening for diabetes and its complications, prevention and control of diabetes. (Devarajan A, 2013)

Across several states through National Programme, screening the high-risk population for the presence of diabetes have started and also referring for treatment after diagnosis. However, follow-up for treatment and day to day management which are the important components of coping remains a challenge for the programme. Since diabetes is chronic in nature and needs every day care, it is necessary to study how people cope with it.

2.4.Coping with type II Diabetes – a Review

Literature on theory and research on coping itself shows that how the construct of coping had undergone several shifts according to the application. Most of the coping research referred to Lazarus and Folkman and their definition of Coping. Earlier work of Lazarus in 1960s on stress and emotion had shown the individual behaviours in stressful events through laboratory experiments and later in the community. Lazarus & Folkman defined Coping as ‘constantly

⁵ Available at <http://www.tnhsp.org/files/Cardio%20vascular%20diseases.pdf> accessed online on 12.09.2014

changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person' (1993, pp.237).

Earlier studies on coping revealed that the approach was entirely oriented in the style or personality disposition of the individual i.e. focusing on the individual factors or individual's behaviour. Later emphasis was given on the process i.e. the interaction of the individual and the environment. A fairly large body of work shows the importance of individual efforts in dealing with the environment to manage specific stressful event. It does not acknowledge how the external environmental factors shape individual behaviour. For example, ways of coping inventory were used to assess the factors by which the individual manages with health or performance in the examination. This is explained by Transaction theory of Stress and Coping. Hence from this point of view, the process of any situation is poorly addressed. (Krohne, 2002⁶, Lyon LB in Rice VH, 2012)

The above definition of coping gives more emphasis on the individual efforts in dealing with specific external/ internal demands (here diabetes). But there are dimensions, which are inter-individual (psychological), as well as intra-individual such as experiential, social, cultural and economic dimensions needed to look into when we look into the requirements to live with diabetes. It includes not only individual efforts but also the condition in which one is living which may allow or provide choices to adapt and cope with the given specific requirements of diabetes. It is not the individual's attitude, skill, knowledge alone is sufficient for one to deal with chronic condition like diabetes. Experience of illness, severity of illness, perception and recognition of the same also plays an important role. The social and material conditions of an individual include age, gender, caste, housing, employment, safe neighbourhood, social role (in family as well as other contexts such as work place, decision making, interaction with family members, their support are also important determinants of coping. Other several factors such as availability, affordability of required health facilities, interaction with health care providers, satisfaction and acceptance of the treatment and also the continuity of the treatment will also have an influence on coping. Moreover, all these are interlinked with each other and also complex. Hence an inquiry at various levels is essential to have a comprehensive understanding of the coping.

⁶Available at <http://www.burnout.nl/docs/Krohne-Stress-history-overview.pdf> accessed online on 18.05.2014

The available literature (DiMatteo RM M 2004; Nam S 2011; Joyce P et al., 2012; Yesudian C AK et al., 2014) on coping with diabetes is mostly informed by a Biomedical or Behavioural approach. Based on the review, the broader domains identified in understanding the coping are

- Treatment adherence / Compliance,
- Doctor-Patient Relationship,
- Social Support,
- Cost of Illness and
- Quality of diabetes care

Studies adopting a biomedical or behavioural approach have focused and emphasized more on responsibility of the individual who is affected with diabetes in taking care of their treatment requirements. They were largely assessing the individuals' skill or capability about how far the individuals could adhere in treating diabetes as per health care provider's advice. In short, the individuals' efforts in accomplishing the task of glycaemic control.

An extensive review of literature from 1989 to 2012 was conducted to identify the role of personal and environmental characteristics in diabetes outcomes. The authors identified positive characteristics such as self-efficacy, self-esteem and adaptive coping (effectively dealing with a stressor) were showing association with glycaemic control among people with type II diabetes. Examples of the tools used in measuring self-esteem, self-efficacy and adaptive coping were self-efficacy for diabetes management, Rosenberg self-esteem scale, Responses to stress Questionnaire, Coping Inventory for stressful situations etc. Whereas parental monitoring and support had played a key role among adolescents with type I diabetes (Joyce P et al., 2012).

A quantitative review of 50 years of research on adherence and assessed adherence rates and variation in adherence, found highest adherence rates among patients of HIV, gastroenterological disorders whereas lowest in pulmonary disease and diabetes. The main factors which were identified for understanding and predicting better adherence were Doctor-Patient relationship, patients' cognitive skill, patient resources such as financial support and social support (DiMatteo RM, 2004). Similarly, Nam S (2011) in their review from 1990 to 2009 had summarized perceptions of patients and also providers about barriers in diabetes management. Culture, language capabilities were found to have influence on patient's health attitude and literacy. Other factors such as financial resources, co-morbidities and social

support also had an impact on self-management of diabetes among patients whereas attitude, beliefs and knowledge of Clinician's also had an influence on diabetes management.

In addition, the literature also showed the role of satisfaction of patients with treatment, perceived value of health and glycaemic control, issues in following dietary regimen. There are other studies that point out economic burden in treating diabetes with its various complications and variation in cost of illness among people across low and high socio-economic class (Shlenk EA et al., 1984; Shobana et al., 1998; Tharkar S et al., 2010; Barbosa et al.; 2012). All the studies have focused one or the other aspects of the adherence issues in treatment regimen.

There are studies focused on how diabetes care is provided in the health services, it's nature and quality in terms of procedure, tests, advice for treating of diabetes and prevention of complications. A study by Tharkar S et al (2015) had shown the differences in diabetes care received from health care providers such as doctors in government hospitals, private General practitioners and Specialists. Other studies had shown gaps in treatment guidelines and real-life practice, clinic profile and glycaemic control, challenges in providing and receiving diabetes care from providers and patients, external barriers to patient other than subjective attitude, knowledge, skill and which includes social and environmental issues including health services. These studies also brought out certain external barriers in accessing health services such as the cost of illness, proximity to health facility, timings of doctors, lack of consensus for standardized guidelines for diabetes treatment among doctors (Zgibor and Songer 2001, Joshi et al 2008; Ramachandran et al., 2008; Tharkar S et al., 2015).

Few studies which have theoretical frameworks are adopted from Health Behaviour theories such as Health Belief Model, Theory of planned behaviour, Bio-Psychosocial model, Attachment theory and some used coping scales to assess the coping strategies in glycaemic control (Ciechanowski PS et al, 2001; Sridhar G R and Madhu K 2002; DiMatteo RM, 2004; Sevilla G E et al 2011). Again, the studies are quantitative in nature, which describes or summarizes the factors which are responsible for either facilitating or affecting the adherence to treatment regimen.

Majority of the studies are clinic based and there are very few are community-based population studies. There are very few studies, which inform the social and cultural aspects of coping with diabetes.

2.5. Social and Cultural aspects of Coping with Diabetes

These are mostly narratives and explanatory models, which depict the process of lived realities of people with diabetes (Drummond N 1990 and Mendenhall E 2010). Drummond argues that care for diabetes does not lie in the black and white reality of scientific determinism. It is embedded in the complex interaction of the peoples' everyday life. He shows that peoples' living requirements are prioritized before taking care of diabetes. Mendenhall E (2010; 2012) and Weaver LJ and Mendenhall E (2014) have tried to illustrate how experiential, psychological, and biological aspects of diabetes intersect with social experiences and how this interaction often produces co-morbid conditions like depression. A qualitative study among urban North Indians had brought how the people with diabetes in different socio-economic groups experience and understand diabetes, linking stress or tension as a cause and consequence of diabetes (Mendenhall E et al., 2012)

Mendenhall E (2012) depicted how accumulated structural violence, limited opportunity for education, lifetime poverty syndemically interacts with the physical health (diabetes) and mental health (depression) and which might further worsen their health status with the presence of complications. Weaver LJ and Mendenhall (2014) tried to explain how people's lived experiences have an impact throughout the life course of an individual. For example, they took the case of a Mexican American woman who experienced violence and was isolated from her family due to immigration problems, she was dependent on the daughters' family and abused by them and thus had a negative impact for treating her diabetes. Another qualitative study done among African – American women has revealed the role of multiple-caregiver in the family and symptom of tiredness are the two major complex issues that influence self-management. Spirituality has emerged as an important factor in general health, disease adjustment and coping (Samuel H et al, 2000)

Drawing from Kleinman's explanatory model of illness, Cohen et al (1994) tried to demonstrate how the patients perceive diabetes as a social problem and its' impact on their lives and how professionals explain diabetes as a patho-physiological problem and its impact on the physical body of the patient. The findings of Loewe and Freeman (2000) also goes parallel with Cohen et al (1994) who emphasize that this kind of explanatory research among patients and providers might lead providers to think about care in a broader context and contribute to 'more reflective practitioner'. Whereas Loewe et al in their work argue that Physicians narratives are similarly complex and it is important to give attention to "some of

the ways in which doctor's stories about diabetes are shaped by the cultural and class differences between patient and provider" (1998:1268).

Goenka's (2002) study in an urban Delhi captured how patients from different socio-economic groups initiate their treatment seeking and follows the trajectory of 'doctor shopping' and monitoring the treatment among people affected with diabetes. She also tried to explain how the doctors practice treatment for diabetes in various health set ups and the networks between the general physicians and the specialists in providing diabetes care.

When the dimensions of treatment seeking behavior are studied, it is not only the presence of illness but also the severity, proximity to health facility, social role, broadly the living condition which allows or limits the people to seek treatment (Banerji D and Anderson S, 1963). Drummond and Mason (1990) emphasize the importance of social context, perception and understanding of the disease and their priorities in life other than taking care of treatment. Their study also demonstrates how extra individual factors or social circumstances remain as treatment barriers. This alters the notion of clinician's dominant bio-medical perspective / behavioral perspective which reiterates the individual responsibility in treatment seeking and adhering to treatment regimen. Similarly, Baru RV emphasizes more on the complex interactions which influences health behavior and states that:

'The severity of symptoms itself is not the only factor because disease is not merely the pathological aspect alone but the recognition that disease dislocates people at an emotional, social and economic level. All these three factors along with the availability, accessibility and responsiveness of institutions influencing health seeking behaviour of a population' (2005, pp.47)

It is also important to understand how people experience, perceive, recognize and understand their illness and their meanings and connotations they give it from their larger social and cultural context. For example, Mendenhall (2010) argued through her narratives that somatic symptoms are expressed by persons affected with diabetes through their psychological experiences which are linked to larger contexts of chronic stress, such as structural violence and migration-related experiences among Mexican Americans.

Raphael D (2003) adapts the social determinants framework to explain diabetes incidence and its management in Health Canada. Based on an extensive review of published studies on the determinants of the management of diabetes, he emphasizes the importance of the social and material conditions that shapes the everyday experience of the disease and its management.

It is also important to note that there are variations in illness experiences and also treatment seeking behavior within and across class and gender and inequality in diabetes care the people with diabetes received.

2.6. Caste, Class and Gender – an understanding of different social layers in coping with diabetes

The understanding of different social layers and its intersection over caste, class and gender in understanding illness experiences is complex. This intersecting caste, class and gender in studying health will give the picture that how one's social condition shapes health and health behavior, it will also show the differentials i.e. inequality in health patterns within and across different socio-economic groups. The inequality in health and in-equal accessibility to health care services is evident in a country like India (Qadeer I, 1985; Baru RV, 2012; Ravindran S et al., 2014). These differentials will implicitly throw light on the unequal distribution of resources, power in attaining health. Very few studies are available in the area of diabetes care pertaining to caste, class and gender intersections.

A systematic review from 2002 to 2012 on quality of care among type 2 diabetes patients shows an association of low socio-economic status and residential area deprivation with worse attainment of health care delivery and health indicators such as high HbA1C, high lipid level which results in other complications (Grintosva et al., 2014). Few other studies have shown class differences in expenses towards diabetes treatment. The people belonging to lower income group would spend a higher proportion of their income than their counterparts in high income group. The disease condition makes poor the poorer as they made the payment for treatment through debt or by mortgaging or selling properties whereas the high-income group spent through savings or insurance (Ramachandran A et al., 2007; Tharkar S et al., 2010:2015).

There studies showed the gender differentials in psychological adjustments and quality of well-being among people with diabetes and identified that the men were having better adjustments in living with diabetes compared to women (Sridhar 2002; Veena S 2001). Women were found to be having less positive well-being with presence of anxiety and depression (Siddique AM 2013). Another study pointed out men who are living with spouse and who are in higher income groups show better score on self-care behaviours and quality of life and women who are divorced, widowed had shown poorer quality of life (Gopichandran

V, 2012). It is discussed above (Weaver LJ and Mendenhall E, 2014) how a woman from a poor socio-economic condition, moreover an illegal immigrant Mexican American going through lots of issues in social life and the health outcome as poor control of diabetes.

Using an interdisciplinary approach, a qualitative exploratory study was conducted in urban Chennai among individuals across income categories (Devarajan A, 2013). This study found that the severity of symptoms is not the only determinant in treatment seeking. The individual's education, occupation, economic position and social role; responses of the providers in the health services, affordability towards health services are the other important factors. In case of women, multiple roles at work and home especially in joint families, marital status play an important role in coping with diabetes. It is observed that the other family members are not even aware of the condition and the sufferings of the individual (particularly for women). It is only when it interferes with daily routine is their recognition of the problem. But among males, their diet and administration of medicine is taken care by women in the family. Class and Gender variation is wider and evident in coping patterns in terms of food, its type, distribution and preference, treatment seeking, monitoring of blood sugar, type and place of treatment (public /private), decision on expenses, visits to doctor.

This study shows the typical contrast in the patterns of coping across income groups. It shows how a woman from low income group struggled to have three meals per day. In contrast woman from the high-income group was able to plan and follow a balanced six meal pattern which is suggested by doctors for diabetes control. This contrast is also observed in how they treat and monitor their diabetes and find time and space to exercise. Women from low-middle income group said that 'Where to walk in this crowded and congested road, if we do not have work at home we can go to the park like men' (pp.99). Once again the difference is seen in woman in the high income who found the space and time to get dropped and picked from beach for her 30 minute walk every evening (Devarajan A, 2013).

2.7. Life course Experiences and Health

Studying gender and class discrimination in terms of health consequences will give an in-depth understanding of who, why and how those are affected. This is well demonstrated by Nancy Krieger (1999) through Eco-Social framework. She explains how peoples' experiences at the direct (self- reported measures) level and indirect (observed / unobserved) level through race, ethnicity, age, gender which complement each other informing the process of

discrimination. She emphasizes on the concept of 'everyday' in experiencing discrimination and how accumulation of these experiences would have an effect over lifetime and health responses. Weaver and Mendenhall's (2014) work also shown how the accumulation of life course experiences such as immigration, structural violence and discrimination among Mexican Americans was internalized and expressed as a health cause and consequence i.e. onset of diabetes and depression and its' impact on availing treatment and everyday management.

Hence all these mentioned factors related to discrimination and the process have to be considered and captured carefully while conducting a study to understand health disparities and similarly when interpreting the data collected within and among different social groups. In short, the larger social context of the individuals has to be investigated comprehensively.

CHAPTER 2
RESEARCH METHODOLOGY

2.1. Summary of Available literature on Coping with type II Diabetes

The conceptualization also largely depends on the available literature and hence summarizing the available literature related to social dimensions of experiencing and coping with diabetes from the previous chapter is/as follows

- Subjective experiences in experiencing and managing treatment of diabetes (individual, household level)
- What are the important determinants in getting treated their condition related with diabetes and role of adherence in better glycaemic control
- Explanatory models of understanding about diabetes among Patient and Providers in the same set-up
- Brought out the social link between stress and diabetes / depression and diabetes (life-course perspective) and how it is situated and connected within the larger social context

2.2. Gaps in the Literature

The important determinant in coping such as interaction between the health services and the diabetes patients (availability, accessibility, affordability and acceptability) is addressed sparsely. The variation in coping patterns was not adequately captured as their study participants were homogenous groups. For example, Mendenhall (2010) had shown the living experiences of Mexican Americans who are unemployed or uninsured. Although Mendenhall E et al (2012) tried to show how people among different socio-economic groups perceive, experience diabetes, their access to health services but their interaction was not captured adequately. It brought out the number of social stressors which affected diabetes. Gender differentials and family dynamics in managing diabetes were also studied inadequately. For example, questions like ‘who makes decisions about your diabetes care?’ was not elaborated. The responses to ‘where do you seek care?’ how often? had given insights into source of treatment, their continuity of treatment (intake of drugs), affordability and issues such as transportation to the health services. But how did people deal with other aspects of treatment such as diet, exercise in their everyday life remained unclear. Again, within the same income group, the experience might vary depending on the duration and severity of diabetes (presence of complications) and that needed to be studied.

Similarly, Weaver LJ and Mendenhall E (2014) have shown the link between diabetes, depression and stress among urban poor in India. This study would give a comprehensive understanding of coping if the interactions of people with health services would have been captured. In a country like India, where health disparities are evident, it is also important to study the variation in coping patterns among people within and across social groups.

It is apparent that adapting an interdisciplinary enquiry of social, economic and psychological interaction in experiencing and managing diabetes at multiple levels such as Individual, household, Institutional level will provide a comprehensive understanding of coping with diabetes.

In order to have an in-depth understanding on coping with diabetes and to overcome the above-mentioned gaps, the researcher had conducted a qualitative exploratory study among people with type II diabetes in Chennai as part of her M. Phil research (Devarajan A, 2013). This study had adopted the conceptual framework of Banerji and Anderson (1965) and which had set a typical example of how an interdisciplinary inquiry could be applied in studying the symptom experiences of people about tuberculosis from social, psychological, pathological aspects and aspects of health care services in response to tuberculosis and had shown how this could help in building a public health approach in the prevention and control of tuberculosis.

Hence, the researcher has tried using this framework through various social, psychological, economical concepts in studying the process of people's experiences in living with diabetes from onset to treatment and further everyday coping with diabetes at multiple levels such as individual, family and at the level of health services. Eighteen people with diabetes from within and across income groups were purposively selected for the study. This brought out an in-depth understanding of treatment seeking process and how the socio-economic position of the individual plays an important role in everyday coping and which includes various dimensions which also have a complex interaction with each other.

For example, this study has shown that multiple resort pattern is an important coping mechanism. If one looked into it carefully that when someone started, seeking multiple remedies it is not only one's economic condition or belief in one system of medicine which push oneself to other system of medicine but it is also the responses of the health care providers which also have an impact on treatment seeking behaviour. From this study it is evident that health services deal with biochemical aspect (level of glucose) of the disorder and not the social and psychological aspect of it. Steps for secondary prevention is completely

absent in public health services. The class and gender variation is also evident and which is discussed elsewhere (p.11). Moreover, this study raised several other research questions (given below) which led the researcher to do a research in a rural context.

2.3. Research Questions

1. What would be the pattern of treatment and treatment seeking in the poor health resource settings like rural or semi-urban areas?
2. How do individuals who are involved in agriculture and small scale industries experience and manage everyday needs of the chronic disorder like diabetes?
3. How does caste, class, gender and religion interact with each other in coping with diabetes?
4. Is there any variation within and across caste groups in coping pattern?
5. What is the understanding and the responses of the health care providers in the provision of diabetes care?

To understand the everyday experience with diabetes at the individual level, the household dynamics involved and the complexities in accessibility, availability, affordability and acceptability of the health services related to diabetes care are important to capture the comprehensive picture of coping with diabetes. It is also important to study understanding of health care providers on diabetes and its treatment and process of how they practice in their health care settings and which is missed out in the M. Phil research.

2.4. Conceptual Framework

There are studies which used the biomedical approach which could brought out the factors or variables considered as responsible for better or poor control of diabetes. From table 1, it is understood that different approaches have been used to study the different dimensions of coping. There are studies which explore one or two aspects of how people cope with diabetes. For example there are studies which focused the individual self-care behaviours in managing the treatment aspects of diabetes without trying to make any link between how people perceive their understanding and the severity of the illness from the subjective experiences.

Table 2.1 – Frameworks used in studying different dimensions of Coping

Frame work	Dimensions of Coping studied
Biomedical(clinical)/ Behavioural	Level of adherence and health outcomes Adherence, compliance, self- esteem, efficacy cognitive skill, knowledge, attitude, behaviour, predictors of glucose control focused on Individuals and self-care behaviours with prescribed treatment regimen
Psychosocial/Bio-psychosocial	Individuals and little focus on other social factors Stress, quality of life, social support and biochemical indicators Diabetes and depression or psychological morbidity patterns Coping strategies
Health Economics	direct cost, indirect cost, spending behaviour (financial coping)
Social/ Cultural (Narratives/ Explanatory models)	Social relationships in dealing with health Doctor-patient interaction, family interaction in dealing with diabetes, subjective experiences in social context Focus on lived realities perception and understanding of diabetes among patients and health care providers
Interdisciplinary approach	Social, psychological, cultural interaction in experiencing and managing diabetes – interpreting diabetes and depression as a cause and consequence of stress located in larger context beyond individual Concept of syndemicity and chronicity in bringing out the life course experiences and its impact on life and management of diabetes
Eco-social framework	patterns of health distribution, health consequences/ disparities - layer of social discrimination – age/gender/ethnicity/ religion and larger socio-political context

	<p>multi-layered and interlinking pathways – biological, socio-cultural, historical and political economy</p> <p>different levels</p> <p>experiences of the Individual(direct and indirect) and family level, everyday experience, Community and neighbourhood level, Health care services level</p> <p>multi-level modelling – studying the cumulative effect of discrimination and its health consequences(social production of disease)</p>
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It can also be said from table 2.1 that starting from biomedical approach to Interdisciplinary approach, the extending nature of comprehensiveness is visible i.e. the focus is moving beyond the individual efforts in coping with diabetes to the level of interaction of individual with other levels such as family, neighbourhood, health care services in coping with diabetes.

From the reviewed literature, it can be interpreted that the concept of ‘everyday’ plays an important role as “every day discourse directs actual (here coping) process and is largely shaped by the pressures and demands of the situation” (Thapan M, 2000:252). Here the situation is the diabetic condition as well as the social condition in which one is living and has to perform the roles and responsibilities in everyday life. As mentioned earlier (Krieger 1999) that accumulation of everyday experiences will have an effect over life time and health responses. Mendenhall E (2012) also gives importance on ‘everyday’ experiences as it would throw light on the lived realities of the people. Hence, the focus is given on everyday experiences to understand the social process of one’s life and its’ interaction in various aspects of coping with diabetes.

Hence, this proposed research has combined different frameworks to understand the experiences and coping process among people with type 2 diabetes. Firstly, I consider Kleinman’s framework to study the understanding of patients and providers about diabetes. Kleinmans’ (1980 in Cohen et al 1994; 1988) work on chronic illness through explanatory models broadly showed the patients and providers’ understanding and variation in topics include

- Aetiology, Time and mode of onset of symptoms, Pathophysiology
- Course of sickness (severity/sick role)
- Treatment

Secondly, I consider Mendenhalls' (2010;2012;2014) work which gives a broader understanding of the social process and cultural mechanisms in everyday life of people affected with diabetes. The narratives are focused on acute and prolonged stressors (acute and prolonged) which explain and interpret through larger contexts such as violence, isolation, discrimination in the causation of diabetes. The authors unpacked the social and economic factors which positioned diabetes in the mind-body dualism of diabetes as:

- How narratives about illness experience could be utilized and interpreted in explaining how social stressors are internalized and negotiated by individuals suffering from chronic illness.
- How an interdisciplinary inquiry could be useful in understanding social, psychological, cultural, experiential aspects of diabetes.

Thirdly, appropriate levels have been explored in understanding patterns of coping and disparities in coping through multi –level framework as explained in eco-social theory such as

- 1) Individual level
- 2) Family level / community level
- 3) Health services level

With this conceptualization, this research will address the following objectives

2.5. Research Objectives

a) Primary objective

- To study the social dimensions of coping with diabetes among people living in rural Kancheepuram

b) Specific Objectives

- To study the socio-economic distribution of people diagnosed for diabetes in selected villages

- To study the illness experience and treatment seeking behaviour of people diagnosed with diabetes
- To study the availability, accessibility, affordability and acceptability of health services for treatment of diabetes
- To understand intra-household dynamics in everyday coping
- To understand the interaction of caste, class, gender and religion in coping with diabetes
- To examine the variation within and across caste and class groups in coping pattern
- To explore the understanding of diabetes and its treatment among health care providers accessed by the patients

2.6. Initiation of identifying People with type 2 Diabetes in the rural areas

So, we were in need to identify persons with diabetes in rural areas in order to conduct this study. Tamil Nadu, one of the states with high prevalence of diabetes (13.7% in urban areas and 7.8 in rural areas, Anjana et al., 2011) initiated several activities to prevent and control diabetes as part of Tamil Nadu health Systems Project. Diabetes screening programmes were also conducted since 2008. Hence consistent efforts were taken since 2013 to approach health authorities of Govt. of Tamil Nadu in order to access the district information on diabetes screening and people with diabetes in the rural areas for framing the method and design of the research. The Health authorities approached were State Programme Officer, National Programme for Control of Diabetes, Cancer and Stroke, Scientists at National Institute of Epidemiology (NIE) (Health Systems Project), Epidemiologist (State Surveillance Unit) the Joint Director and the Deputy Director, the Director of Public Health and the Health Secretary. There were no formal responses received from the government authorities and hence simultaneous steps were taken to look for other data sources for people with diabetes in rural areas of Tamil Nadu. Then we had approached Rural Women's Social Education Centre, a NGO which is extending health care services to people affected with diabetes in the selected villages of Tirukalukundram block of Kanchipuram district of Tamil Nadu and received positive response. Hence, it was decided to select all the people with diabetes living in these villages as study participants for this research.

Before describing the method and design of the study, it is required to give a brief introduction about RUWSEC.

2.6.1. RUWSEC - Rural Women Social and Education Centre and initiation of NCD clinic

RUWSEC was established by a team of 13 women in 1981 and 12 out of 13 were belonging to the local villages. Since three decades, they are working for the advantage of socially and economically disadvantaged populations in Tiruporur and Tirukazhukundram blocks of Kanchipuram district, Tamil Nadu. Majority of the population they serve belonged to the Scheduled caste. RUWSEC importantly focuses on gender equality, sexuality and reproductive health and related rights. Initially RUWSEC has implemented Community-based action for health promotion through building community cadres such as Self-help groups. It has also started a reproductive health clinic to benefit the health of the poor and the marginalized. Gradually, this reproductive health clinic started providing general health services by promoting the alternative medicine system such as Siddha and Homeopathy.

The health care providers in RUWSEC could observe that people affected with diabetes and hypertension were increasing gradually and therefore, they started running a diabetes clinic every week during 2012. They also started screening the people for diabetes and hypertension in the community since August 2013. Initially they conducted camps in 6 villages where they were testing fasting blood glucose to detect people with diabetes. Later, they started doing house to house survey to identify people at high risk. The modified Indian Diabetes Risk Score (Mohan et al 2005) was used to identify the people at risk for diabetes. Once the individual was identified to be at risk, the individual was advised to test their blood sugar. Those individuals had either visited RUWSEC's diabetes clinic or other PHCs or CHCs or private labs and clinics for their blood test.

The health workers of the respective villages also had a check that whether they went for blood test or not. As RUWSEC works for the marginalised and vulnerable groups, it mainly focuses the villages where Scheduled Castes reside. In addition, they also extend health care services to people from Most Backward Castes through clinic services as well as community programmes such as health awareness programmes or campaign for diabetes prevention or tobacco control or any other health events. The health workers also used to monitor the people with hypertension and cancer in addition during their village visit and educate them on diet, physical activity and regular intake of medicines. The peer (support) group meetings were

also conducted once in a month at RUWSEC as part of their activity. During the meeting, different aspects of diabetes and its care would be discussed by the health care professionals. The patients would also discuss their experiences and support each other. The healthy meal preparation would be demonstrated and also exhibited there to motivate people consume healthy food

The monitoring of people with diabetes belong to the most backward and backward caste groups also happened gradually when those people visited RUWSEC's diabetes clinic for treatment or else informed by other patients in the village. As the house to house survey was not done in these villages where the most backward / backward caste groups reside, the chance of missing count of people with diabetes might be higher.

Moreover, it was observed that even after the house to house survey was done among the Backward Class Muslims there were more women (equal to 27) found to have diabetes whereas fewer men (equal to 5) were found to have diabetes. Later it was clarified by the health workers that men either did not report for risk screening or did not proceed for blood test after they were found to be at risk.

As a first step, I formally visited RUWSEC to explore the feasibility for conducting the research in their working area (target villages). The permission was also obtained formally to access their data base. The visits were made to the villages and took part in the health education programmes conducted by RUWSEC to get familiarise with the people.

2.7. Method and Design

People who were diagnosed with type II diabetes and residing in these selected 25 villages (given in Annexure- II) of Tirukalukundram block were considered as study participants. This study included both quantitative and qualitative method.

2.7.1. Selection of Study participants

Who were the study participants?

- **People diagnosed with diabetes and having duration of minimum 6 months**
- **Health care providers accessed by the people with diabetes**

This research study was done in two phases. The first level of inquiry was a quantitative survey and the second level had employed a qualitative in-depth study.

The list of people with diabetes was collected from RUWSEC. House visits were made and the people with diabetes belonged to scheduled caste group (who might be considered as representative as each and every one was given equal chance of screening and diagnosis) was approached first to conduct the first phase survey. A list of 376 people was taken from the data base and conducted a first phase survey among 252 (148F, 104M) persons with diabetes. In order to achieve the representation from other caste groups, the people with diabetes from most backward, backward and forward caste groups were surveyed purposively.

2.7.2. Tools and Techniques

The following details were collected from people with diabetes during first phase survey using an interview schedule through face to face interview.

- Household Characteristics (social and demographic characteristics such as age, gender, occupation, Income, Caste, family type, details of the family members, landholding, house type)
- History of illness (perception and experience of symptoms, age at onset, duration, co-morbidity, complication)
- Treatment seeking prior to screening and after screening (recognition and experience)
- Treatment of Diabetes

Availability of health services

Accessed to _____Allopathy/ Ayurveda/ yoga/ Unani/ Siddha/ Homeopathy/
other system of medicine/ formal/informal/public/ private

Affordability: expenses direct / indirect

Monitoring – Visits to doctor, Investigations

Descriptive statistics is used to analyse the quantitative information collected as part of the first level of research using SPSS.

When the study was in the planning stage, it was decided to have a purposive sampling of study participants to conduct the second level of study i.e. a qualitative in-depth interview on everyday experience of diabetes and other important aspects of coping. As a first step, it was proposed to prepare a matrix (given in the Table 2.2) based on the survey by stratifying the caste groups into occupational groups (as per census classification) and then further stratify

the participants based on the gender and severity of the disease presence and absence of complications. It was believed that this design would ensure the inclusion of study participants from all the class within and across caste groups. But the discussion happened after the first phase survey had thrown some light on the complexity of hierarchy exist in the given context of the research area. It was understood that the matrix we prepared might miss this wider complexity and it would show a narrow picture. Then it was further discussed and decided to refer to labour aspects given by Daniel and Thorner (1962). This is further explained in the forthcoming chapter (Chapter 3). For example, the category cultivators may include a small peasant, middle peasant, rich peasant and landlords and further absentee land lords.

This first survey was considered as a base to have a broader understanding of the socio-economic context of the study sample. It served as a base to calculate (crude) prevalence of diabetes in the selected villages and further socio-economic characteristics and the treatment profile of the patients were also useful in selecting the patients within and across caste and class groups for conducting in-depth interviews in the second phase of the study. The severity of the diabetes in terms of presence or absence of complications was considered in selecting the participants for the in-depth study on the process of coping with diabetes. This process is further explained and given in the chapter 3. In-depth interviews were conducted among 54 patients (32F, 22M).

In addition, the health care providers who were accessed by the patients for treatment were also identified and interviewed. The patients had accessed the providers across public, private (for profit) and private (non-profit) health facilities and also from different systems of medicines such as Allopathy, Siddha, Homeopathy and 'Accu Touch'. The permission was obtained from the Directorate of Public Health and Deputy Director of Health Services (DDHS), Health Unit District (HUD), Saidapet to approach Health care providers at the primary health centres serving those 25 villages. The health care providers at the private clinics/hospitals and private (non-private) clinic, RUWSEC were also approached and included as part of the study.

As the researcher became well aware about people, socio-economic condition and severity of diabetes when she was in the end of the first phase survey, she started approaching the people with diabetes for in-depth interviews. It took almost a total duration of nine months for the researcher to explore and became aware of all the twenty-five study villages. It can also be

An **Interview guide** is used to collect data from the health care providers. A guide is framed based on the works of Goenka S (2002)⁷ and Loewe R et al (1998)^{8,9} to understand the knowledge and practice of the health care providers in the provision of diabetes care.

First the tools were constructed in English and translated to Tamil and back translated from Tamil to English to have a check on the reliable meaning. Then the tools were also piloted to check the reliability and validity. As the native language of the participants (people with diabetes) was in Tamil, data was collected in Tamil. For the health care providers, the interviews were conducted either in English or Tamil according to their convenience.

The interviews were tape recorded after obtaining the consent from the participants.

Field notes

Every observation related with the survey or interviews were noted everyday separately either during the field work or at the end of the field work. This field notes were useful when the researcher could not tape record the important information which were relevant to the research. These field notes were also useful when the participant was not willing to give consent to record his/her interview /responses as part of the interview. Sometimes, during some informal discussions, the participants would happen to share some important aspects of his experiences which might be relevant to the research. ‘Note taking’ was then useful in documenting the information to some extent. It was useful when the follow up visits were made to the participant’s house to know about their health condition and the treatment process. There was few information which could be collected only through observation, which could not be audio recorded but could be recorded in the form of notes. For example, the activities which took place at the house hold level such as the preparation of food, distribution, timings, how the foot ulcer was taken care of and how the insulin was taken, how the care was given in case of older adults etc.

⁷Goenka, S., 2002. Health practices and beliefs of patients and Medical Practitioners in Relation to Diabetes. All India Institute of Medical Sciences, New Delhi.

⁸Loewe, Ronald, John Schwartzman, Joshua Freeman, Laurie Quinn, and Steve Zuckerman 1998 Doctor Talk and Diabetes: Towards an Analysis of the Clinical Construction of Chronic Illness. *Social Science and Medicine* 47(9):1267–1276.

⁹Ron Loewe and Joshua Freeman 2000. Interpreting Diabetes Mellitus: Differences between Patient and Provider Models of Disease and their Implications of Clinical Practice. *Culture, Medicine and Psychiatry* 24: 379-401.

2.8. Data analysis

The recorded interviews from the in-depth interviews were transcribed verbatim into text and then translated from Tamil to English. Thematic analysis was used to analyse the qualitative information.

2.8.1 Thematic Analysis

Thematic analysis is “a method for identifying, analysing and reporting patterns (themes) within data” (Braun & Clarke, 2006: 79). The transcripts were organised in a systematic way, read thoroughly, coded and then identified the common emerging themes and patterns; further, it was categorised into themes or patterns falling under broader domains and then sub domains were listed down under each major domain. This would be seen in each chapter presented here.

Field notes were included when the data was analysed.

2.8.2. Case Study

Case studies were used to understand and explain the process of complex social, financial and psychological interactions in coping with diabetes appropriately.

2.8.3. Explanatory Model

An explanatory model was constructed to explain the understanding and practice of the health care providers in the provision of diabetes care within and across systems of medicine. The framework as mentioned in the conceptualization has been appropriately utilized to interpret the results.

2.9. Ethical clearance: Ethical clearance for this research was obtained from Institutional Ethics Review Board of JNU. Similarly, participants were included in the study after a written/verbal informed consent was taken by explaining the purpose and procedure of the study. Confidentiality of the study participants was maintained throughout the research and would be continued up till the dissemination and publication of the research in order to protect identity of the study participants. This proposal was submitted to RUWSEC in order to get approval from their institutional authorities.

The individuals with diabetes had spent their valuable time and information for the surveys and in-depth interviews conducted as part of my PhD research. The information

would include not only their knowledge, understanding, experience and treatment of diabetes but also included familial and social context. This actually raised an important question that what would be my returns which would benefit them in turn? This situation actually left the researcher in an ethical dilemma and raised the question that as an individual researcher, what would I be able to do? This dilemma was not fully but partially resolved by the presence and role of NGO (RUWSEC) which involved in running the health programme for the people with diabetes. The researcher took part in the activities of RUWSEC to some extent such as the preparation of materials which were utilized for giving health education on understating of diabetes and healthy diet and other health campaign and awareness programmes for the prevention and control of diabetes. As this research tried to look beyond the individuals affected with diabetes, this might be helpful in giving additional insights in addressing the felt needs of the people.

It was discussed with RUWSEC that the research data could be shared after the submission of the PhD thesis and final evaluation which is viva- voce by the Centre of Social Medicine and Community Health, Jawaharlal Nehru University.

Chapter 3

Socio-Economic Characteristics, Disease and Treatment profile of the study participants

3.1. Geographical profile of Kanchipuram District

Kanchipuram district was previously called as Chengalpattu district and later in 1997 Chengalpattu was bifurcated into Kanchipuram district and Tiruvallur district. It is located in the north eastern coast of Tamil Nadu. Around half of the population depends on the main occupation of Agriculture and related activities. Palar is the main river flows in the district. Majority are rain fed areas and receives most of its water supply from the South West and North East monsoons. The major sources of water supply are tanks and wells. If rainfall fails during the season, it would affect crop production which is mainly paddy¹⁰¹¹.

3.2. Socio-Economic, Demographic and Health profile of Kanchipuram District

The demographic profile of Kanchipuram district and Tirukalukundram is given in table 3.1 comparing with the state facts and figures. Kanchipuram constitutes around 5.5% of the total population of Tamil Nadu. About 64% of its population is in urban area which is higher than the State average i.e. 52% and 36% lives in rural areas while 48% lives in rural areas of Tamil Nadu. It is important to note that around 42.1% and 40.7% of the working population of the state and Tirukalukundram block are involved in agriculture and related activities. Compared to the State average, only 21.6% of the working population are involved in agriculture and related activities in Kanchipuram district¹² (census, 2011).

Paddy is cultivated even thrice a year if there is good rainfall. It is observed that the landless people also try to rent land (in terms of paddy or money) and cultivate paddy. People used it for selling and also keep some amount for their own use. There are different kinds of land tenancy seen in general and some of which are also observed in the villages of Tirukalukundram block. For example, if someone has taken 1 acre of land and cultivated paddy by spending all the expenses on their own, then they need to give one third of the production. The other type of tenancy is when the land owner and the tenant spend the money equally and divide the produce equally. In this case, the tenants would take care of the labour required throughout the cultivation.

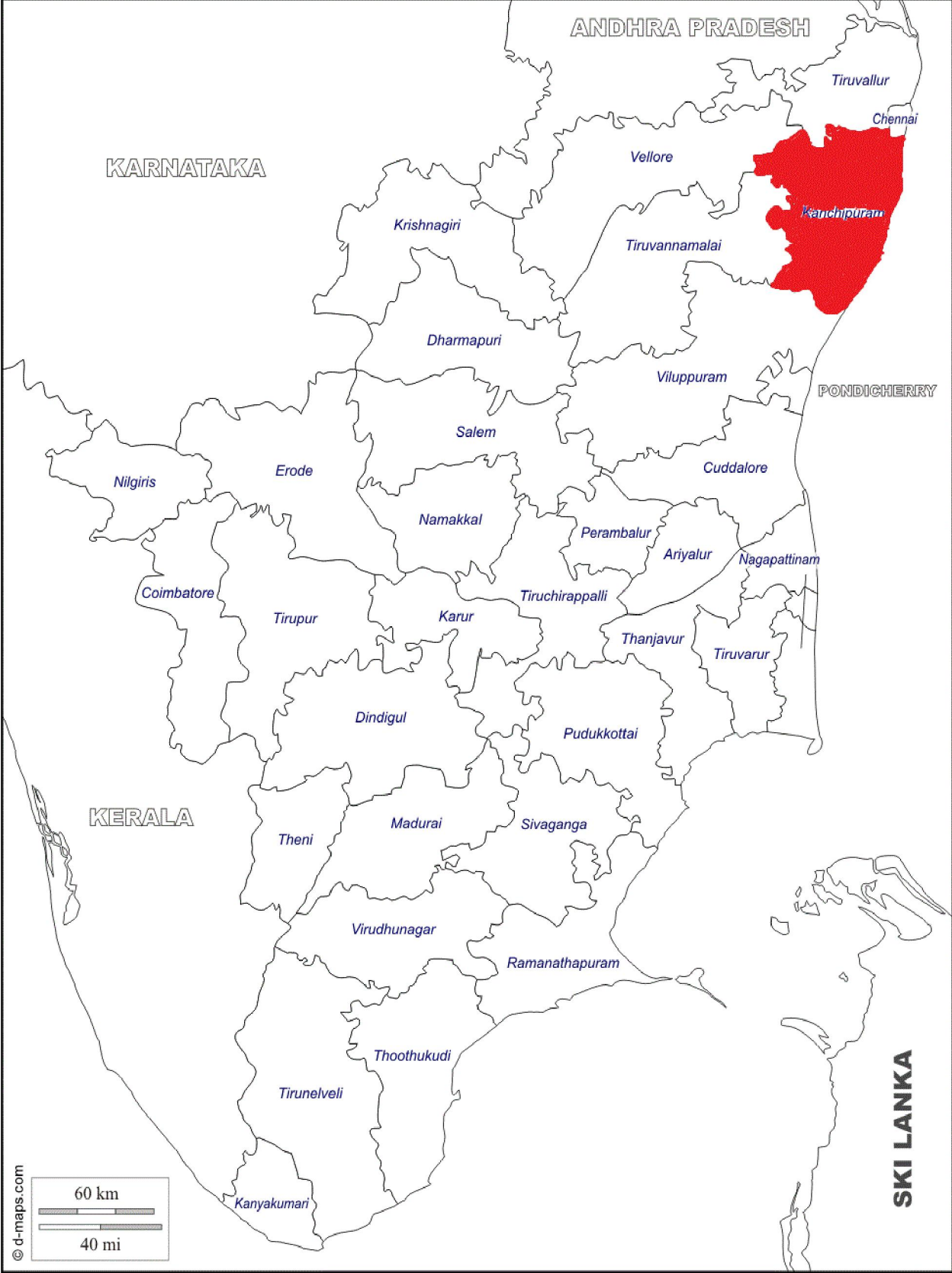
Half of the working population depends on other forms of employment in the state and block whereas one-third of the population in the district depends on employment in the district. The

¹⁰<http://dcmsme.gov.in/dips/2016-17/DIP.KANCHEEPURAM.2015.16.pdf> accessed online on 20.05.2018

¹¹http://kanchi.nic.in/Aboutdistrict/dhb_2015_16.pdf accessed online on 20.05.2018

avenues of employment include manufacturing, construction, trade, retail business activities etc.

Map 3.1: An Overview of Kanchipuram and Tirukalukundram



Map 3.2: An Overview of Tirukalukundram Block



The building and promotion of small scale business and industries started increasing gradually during the last two decades in and around the district. This resulted in the movement of population from rural areas started to view these enterprises as sources of employment despite the long distance. The promotion of small scale industries is confined mainly in the Special Economic Zones (SEZ) located at Sriperumpudur, Tambaram and Maraimalainagar which are approximately 50 to 60 kilometres from the villages of Tirukalukundram block. Out of 31 SEZ in Tamil Nadu, 14 are in Kanchipuram district and a total of 203 units are functioning¹³. There is also an atomic power station which is located in at Kalpakkam which is located at a distance of 8 to 15 Kilometres (Kms) that also employs people on a contract and permanent basis.

Kanchipuram is also called as the temple city and similarly Tirukalukundram block which is located in the Kanchipuram district also has a number of temples. The name Tirukalukundram has also a special story and a famous temple “Vedagiriswarar” of Lord Shiva

¹³Vijaya Kumar N(2013), A critical study on problems and prospects of special economic zones in Tamil Nadu with special reference to kanchipuram district, PhD Thesis available at <http://hdl.handle.net/10603/125278>

is located there. It is said that the eagles used to visit hill top of the temple every day and the temple priest used to serve them food grains. It is believed that the rishis or Hindu sages who were turned into vultures by Lord Siva are paying homage to Lord Shiva to achieve salvation. In Tamil, eagle is called a “Kazhugu”. As Kazhugu used to visit the hill every day, and thus the place is named as Tirukazhukundram¹⁴ (Thurstone E, 1958 p.282).The authors said that the birds are not eagles and they are Egyptian vultures. Every year, there will be the celebration of this temple festival lasting for 11 days during the month of April (Tamil month – Chithirai).

Tirukalukundram is the main town where the important markets mainly grocery, clothing, vegetables and fruits are available. Non-vegetarian items like fish, mutton, chicken and beef are also available. It is also found that the small vendors used to sell vegetables and fish in the villages too. As the coastal areas like Sadras is located very close to these villages, consumption of fish is very common among this population. It is also important to note that many super markets are also available and the numbers are increasing gradually. Small petty shops and grocery shops are also available in the villages.

It is important to note the presence of two TASMACH shops within the reach of 10 kilometres and the joint outlets of fast food shops which are also situated closer to the villages and easily accessed by the men.

Table 3.1: Socio –Economic and Demographic Profile of Kanchipuram District

Key Information	Tamil Nadu	Kanchipuram	Tirukalukundram
Total population	72138958	1861789	151950
Male	36158871	937665	76621
Female	35980087	924124	75329
Urban	34,917,440	2,538,336	21,151
Rural	37,229,590	1,459,916	130,799
Percentage of urban population	48.4%	63.9%	13.9%
Sex Ratio (No. of females per 1000 males)	996	986	1018
Child Sex Ratio (0-6)	943	959	1008

¹⁴ Katie Fallon, Hill of the Sacred Eagles, 2011, available at <https://www.terrain.org/essays/28/fallon.htm>

years)			
SC	14,438,445(20%)	948,081(23.7%)	47,842 (31.4%)
ST	794,697 (1.1%)	41,210 (1.03%)	3,086 (2.0%)
Total workers	32,884,681 (45.58)	1,673,814 (41.86%)	69960 (46.0%)
Non Workers	39,262,349 (54.42)	2,324,438 (58.14%)	81990 (54.0%)
Cultivators	4,248,457 (12.92%)	89,343 (5.34%)	15130 (21.6%)
Agricultural Labourers	9,606,547(29.21%)	272,514 (16.28%)	13375 (19.1%)
Workers in the Household Industry	1,364,893(4.15%)	54,732(3.27%)	1415 (2.0%)
Other Workers	17,664,784 (53.7%)	1,257,225 (75.1%)	37403(53.5%)

(Source: Census, 2011), Tamil Nadu Rural Development Report¹⁵

Table 3.2: Health Profile of Kanchipuram District

Key Indicators of Health	Kanchipuram	Tamil Nadu
Life Expectancy at Birth		
Male	68.6	68.2
Female	71.2	72.3
Birth Rate	15.9	11.1
Death Rate	7.2	5.1
Sex Ratio at Birth	932	923
ANC (covered 3 check-ups)	71.2	88.4
Institutional Deliveries	99.0	100
Full Immunisation	56.2	64.4
IMR	20	20
MMR	79	79

Source: (DLHS – 4¹⁶, District hand book Kanchipuram, 2016^{17, 18} and statistical hand book of Tamil Nadu, 2016¹⁹)

¹⁵ Available at https://www.tnrd.gov.in/databases/census_of_india_2011TN/.../01-Kancheepuram.pdf accessed on 15.06.2016

¹⁶ Available at <http://rchiips.org/pdf/dlhs4/report/TN.pdf> accessed on 24.03.2017

¹⁷ Available at http://censusindia.gov.in/2011census/dchb/3303_PART_B_DCHB_KANCHEEPURAM.pdf accessed on 16.05.2018

Kanchipuram performs better in several health indicators such as ANC coverage, full immunisation and is higher than the state average as represented in Table 3.2. As the urbanisation and industrialization is visible in the district, the transition is also seen in terms of agriculture, food habits. Hence it is important to show what people have shared about the transition that is happening in their social and economic spheres in terms of agriculture, livelihood, income, food preparation and which in turn may have an effect on their health.

3.3. Socio – Economic transitions: Collective memories

When people were interviewed to know their everyday coping strategies with diabetes in (the villages of Tirukalukundram block), many of the elder participants themselves and elder family members of the study participants were trying to share their lived experiences and its association with the onset of diabetes with transition in agriculture, food practice, use of chemical fertilizer in crop production and physical inactivity due to mechanization. For instance one of the elder adult said that

“Earlier we used to cultivate other millets (raagi, sorghum) and pulses, oil seeds(mentioned ground nuts/sesame) with paddy. But now who is bothering about all these? If rain is there people would cultivate only paddy. People started feeding cows also the rice which they get it from PDS (Public Distribution System)”(Mr.GP, 70 years, Kunnavakkam, 05.04.2016)

Similarly, another man from Periyakattupakkam mentioned about the way they used to add several leaves (such as neem) in the land before planting paddy, which would provide energy for paddy growth. He also added that

“Earlier the duration to produce paddy was more and it would take several months and now a days it grows faster even in 90 days and hence compromising the quality and taste. When he was mentioning the taste he added that the fragrance while boiling the rice would be very good then and presently we are getting fertilizer’s (marunthu) smell only. He tried to point out that boiling rice would produce that strong smell, wouldn’t it disturb our body when we consume?”(Mr. R, 30.12.2016)

¹⁸ Available at <https://cdn.s3waas.gov.in/s31543843a4723ed2ab08e18053ae6dc5b/uploads/2018/04/2018042565.pdf> accessed online on 16.05.2018

¹⁹ Available at <http://www.tn.gov.in/deptst/Stat.htm> accessed on 07.08.2017

There were others who mentioned about the use of raagi and other millets and the time they used to take to prepare the raagi gruel. As Mrs. L was mentioning:

“Raagi (horse millet) kanchi (gruel) preparation is a time consuming process. You need to boil water and put the raagi flour into it (a little rice can be added), mix it well and keep it throughout night and allow it to ferment, then in the morning a little portion of it can be taken and add with water and mix it and boil it for some time before serving. People used to consume it as such or add curd or butter milk into it and then have it. Nowadays the young women do not like to take time to prepare it and just boil the rice, no need to stay there but if you prepare ‘raagi coolu’ you need to spend more time and again the availability and affordability of good quality rice became the issue”(Mrs. L, 58 years, Pandur, 08.10.2015)

She continued to say that

“We had ‘raagi kanchi’ or ‘raagi kali’ (raagi ball) those days we also did several physical and tiring works in the house as well as in the agricultural fields. But now who is having such a healthy body to work like that” (Mrs. L, 58 years, Pandur, 08.10.2015)

Similarly Mrs. S was pointing to her daughter in law and said that *“we used to carry heavy bags of paddy after separating the grains or threshing the paddy to separate grains from the straw and you know we used to have food two times a day and we used to do pound rice / flours with our own hands, but these days, people become so tired only by performing the household chores that too with all the machines like mixer, grinder”*.(Karumarapakkam, 29.03.2016)

The importance of exercise in daily life was elaborated by an elderly man who said that as a young man he used to walk to reach his school in neighbouring town which was around 7 to 8 kilometres away. During his college days he used to cycle almost 15 kilometres at the then district headquarters. In addition he used to work in the agricultural fields. He got diagnosed with diabetes in his late 60s while his son became diabetic in his early 30s. He associates his late onset of diabetes to the high level of physical activity during his youth. His son led a much more sedentary life and his grandson does not do any physical activity. He expressed his worry that how the lack of physical activity will affect their health and bring on illnesses at a younger age compared to his generation.

3.4. Prevalence of Diabetes and Social Characteristics of Study population

With an overall understanding of socio-economic, demographic and health profile of the study area, it is important to study the illness (diabetes) in terms of prevalence and the distribution according to Caste and Gender.

Table 3.3: Prevalence of diabetes across Caste and Gender

Caste Group	Total Population in the select villages (> 30 years)			Prevalence of diabetes (total)			People with diabetes (Surveyed)		
	M	F	Total	M	F	Total	M	F	Total
Scheduled Caste	1322	1324	2646	75 (5.7%)	87 (6.6%)	162 (6.1%)	46	59	105
Backward Class Muslim	78	90	168	5* (6.4%)	27 (30%)	32 (19%)	2	16	18
Most Backward Caste	1032	1036	2068	59 (5.7%)	69 (6.7%)	128 (6.2%)	38	51	89
Backward Caste#	395	390	785	19 (4.5%)	24 (6.2%)	43 (5.5%)	14	19	33
Other Caste	56	58	114	6 (8.9%)	5 (8.6%)	11 (9.6%)	4	3	7
Total	2883	2898	5781	164 (5.7%)	212 (7.3%)	376 (6.5%)	104	148	252

Source: Field survey, 2015-2017

- constitutes Mudaliar, Reddiyar, Yadavas, Shanar(Gramini), Naidu, Vannaar

* The Muslim community is living in a village closer to RUWSEC, NGO which had done a house to house survey and screened them for diabetes. As reported by the investigators, more women participated in the screening and further diagnosis whereas men were not participated and this might be one of the reasons for the less prevalence among Muslim men.

As mentioned in the chapter 2, firstly the household survey was conducted among the individuals of 30 years and above in the selected villages by RUWSEC during the year 2013. The diabetes prevalence (period) is calculated using the total number of individuals with diabetes (old and new cases identified during the survey by RUWSEC) as numerator and the total population in the age group of ≥ 30 years in the selected villages as denominators²⁰ and the same is stratified according to caste and gender and depicted in Table 3.3. The other Social characteristics are given in table 3.4.

From the above table 3.3, it is observed that there is not much variation in the prevalence of diabetes among the scheduled castes (SCs), most back ward castes (MBCs) and backward caste groups (BCs) constituting, 6.1%, 6.2% and 5.5% respectively, compared to 6.5% for the total population. However, it is observed that the prevalence among forward castes is 9.6%. It is highest amongst Muslims²¹ (19%) as compared to 6.5% for the total population.

The findings of our primary survey of prevalence broadly correspond to other studies. Previous studies conducted in rural areas of India have shown a prevalence ranging from 2% to 13% (Mishra et al, 2011). The prevalence of diabetes among scheduled caste and other caste groups in our survey is very similar to that of the study conducted in a rural area of Punjab by Tripathy et al., (2017). The overall prevalence of diabetes in Tamil Nadu as reported in the ICMR study is 10.4% which also showed the urban prevalence of 13.7% and rural prevalence of 7.8% (Mohan V et al., 2008). This figure is slightly higher than our present study. The present study shows variation in prevalence among different caste groups. The prevalence of diabetes among the scheduled caste was 6.4% whereas the prevalence among the other backward caste and other caste groups was 10.2% and 9.3% respectively.

It is interesting to note that there is no major gender difference in prevalence across caste groups with a notable exception of the Backward Class Muslims²² despite the difference observed in total gender prevalence (Male – 5.7 and female – 7.3%, $P = 0.0136$). The global prevalence estimated by IDF that did not show much variation across gender. The study

²⁰The number of individuals in the in the age group of ≥ 30 years were enumerated for the study villages separately from the documents collected from the Village Poverty Reduction Project at Block Development Office, Tirukalukundram.

²¹Muslims are categorised as Backward Class Muslims (BCMs) in Tamil Nadu

²²As reported by the investigators, more women participated in the screening and further diagnosis whereas men were not participated and this might be one of the reasons for the less prevalence among Muslim men.

estimated that the prevalence is around 9.1% among males and 8.4% among females (IDF, 2017). Recent studies such as ICMR- INDIAB study conducted in India are showing higher prevalence of diabetes among males than females in the age group of 35 to 64 years whereas males in the age group above 64 years are showing less prevalence than females (Anjana RM et al, 2017). This present study also shows that prevalence among females (15.5%) is significantly ($p = 0.003$) higher in the age group 51-60 years than the males (9.2%). The other age groups have not shown any gender variation in the prevalence and the same is presented in Graph 3.1.

A study conducted in rural parts of Kanyakumari (South India) has shown that males(9.8%) had high prevalence of diabetes compared to females(6.3%) (Jerlin NA, 2011) whereas study conducted in Western Uttar Pradesh (UP) has shown high prevalence of diabetes among females (9.9%) than males (6.8%) (Singh PS et al, 2017). The study by Jerlin has shown that the physically active people such as people involved in exercising, walking and farm-related activities has diabetes prevalence of 4.7%, 6.8% and 8.9% respectively whereas the sedentary group has a prevalence of 23%. The current study has shown an overall prevalence of 6.5% diabetes among the study participants. As majority of the study participants were landless labourers and marginal farmers, the result is consistent with the results of the aforementioned study.

Graph 3.1: Age wise prevalence of diabetes

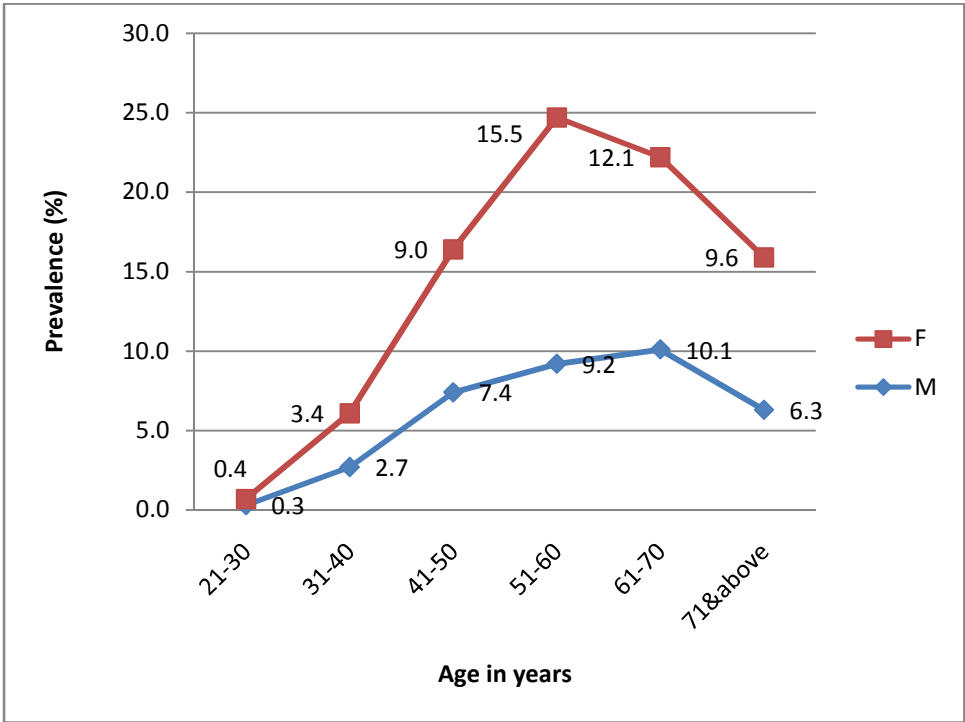


Table 3.4 show that proportion of the female (58.7%) is higher than males (41.3%). The age distribution of participants has shown the gradual increase of proportion as age increases and similar trend is also shown in graph 1. The higher proportion is found in the age group of 56-65 years (31%) and decreases after 66 years. It is noted that around 20% of the participants are widow/widowers and about 40% of the study participants have not received any formal education however of the remaining 60%, 56% school education whereas only 4% of the participants have received higher education after schooling. The majority (61%) of the participants have diabetes for less or equal to 5 years. The other details such as family history and treatment are also given in this table.

Table 3.4: Socio-demographic details of the Study Participants

Details	Number of study participants (%)
Gender	
Male	104 (41.3)
Female	148 (58.7)
Age	
≤ 35 years	11 (4.4)
36-45 years	57 (22.6)
46-55 years	63 (25.0)
56-65 years	78 (31.0)
≥66 years	43 (17.0)
Marital status	
Married	201(79.8)
Widow/Widower	50 (19.8)
Single	1 (0.4)
Education	
No School Education	102 (40.5)
Primary	66(26.2)
Secondary/ Higher secondary	74 (29.4)
Diploma / College	10(4.0)
Caste	
Scheduled Caste	105(41.7)
Most Backward Caste	89(35.3)
Backward Caste Minorities (Muslim)	15(6)
Backward Caste	36 (14.3)
Other Caste	7 (2.8)
Family History of Diabetes	
Yes	51(20.2)
No	201(79.8)

Duration	
≤5 years	155(61.5)
6-10 years	68 (27)
≥11 years	29 (11.5)
Treatment (current)	
OHAs	189(75%)
Insulin	7 (2.8%)
OHAs + Insulin	12(4.8%)
OHAs(Allopathy)+Any other systems of medicine	17(6.7%)
Other systems of medicine	17(6.7%)
Discontinued	10(4%)

Source: Field Survey, 2015-2017

3.5. Class wise distribution of study participants

As discussed in the previous chapter, we have classified our survey population into five socio-economic groups based on land holdings and labour in the given context. They are as follows

- 1) Group I - Landless labourers are the people who are landless and depend exclusively on NREGA or any other daily wage labour including agricultural labour
- 2) Group II -Marginal farmers are people who have agricultural land of up to 2 acres and cultivate it using their own labour and also work outside or work under NREGA
- 3) Group III -Small peasants are people who have two to five acres of land and cultivate using their own labour and also hire the labour outside. They are also engaged in NREGA
- 4) Group IV - Middle peasants who are people owning more than 5 acres of land, cultivate it using their own labour and also hire labour from outside and
- 5) Group V - The participant or any of the family members who holds the government job or professional jobs importantly Engineers or retired from the government job. As the groups III and IV are less in size, they are put together for the purpose of analysis.

The class wise distribution of the study participants based on the above-mentioned classification is given in Table 3. 5. This table has shown that more than half (54.4%) of the participants are landless labourers i.e. Group I while 16.3% Marginal Farmers, 7.1% small and middle peasants and 22.2% are Job holders/retired from government or professionals.

Table 3.5: Class wise distribution of study participants

Class	Number of participants (%)
Landless labourers (Group I)	137(54.4%)
Marginal Farmers (Group II)	41(16.3%)
Small and Middle Peasants (Group III&IV)	18(7.1%)
Government Job/Retired/Professionals (Group V)	56 (22.2%)

When we further stratify caste by class, it is observed that majority of the landless labourers are belonging to the scheduled caste (68.6%) and the backward class Muslims (93.3%). This is presented in Table 5 (a). While the small and middle peasants are high among the other caste groups (71.4%), the government job holders are proportionately higher among the backward caste group (38.9%). It is observed that the landless Mudaliars (one of the backward castes) were holding land 15 or 20 years back and they sold their land and invested that money in constructing houses in the cities or supporting business of their children.

Table 3.6: Class wise distribution of the study participants within Caste

Caste	Landless Labourers (Group I)	Marginal farmers (Group II)	Small and Middle Peasants (Group III and IV)	Government job /Professional /Retired (Group V)	Total
SC	72 (68.6%)	10 (9.5%)	1 (1.0%)	22 (21.0%)	105
MBC	34 (38.2%)	27 30.3%	10 11.2%	18 (20.2%)	89
BCM	14 (93.3%)	0 (.0%)	0 (.0%)	1 (6.7%)	15
BC	17 (47.2%)	3 (8.3%)	2 (5.6%)	14 (38.9%)	36
OC	0 (.0%)	1 (14.3%)	5 (71.4%)	1 (14.3%)	7
Total	137 (54.4%)	41 (16.3%)	18 (7.1%)	56 (22.2%)	252 100.0%

Source: Field survey, 2015-2017

3.6. Age at onset

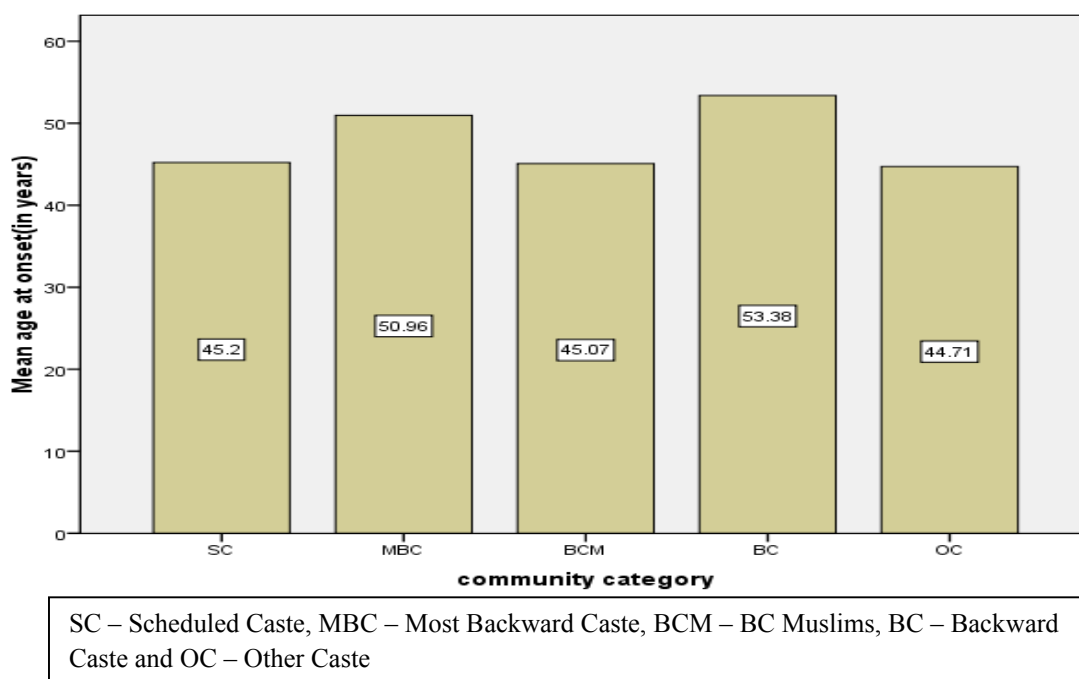
The average age at onset of diabetes is similar for both the male and female participants surveyed. The proportion of male whose age at onset is below 35 years is 9% whereas female is 19% which is statistically significant at $P < 0.001$. The caste difference is also observed in age at onset. The backward minority group (40%) group and the scheduled caste group (19%) have had experienced earlier onset (< 35 years) earlier compared to the other caste groups. The average age at onset between SC and MBC found to be varied but not statistically significant, whereas age at onset for BC is 7 years later than SC and which is statistically significant at $P < 0.001$ and which is represented in the chart 3.1 given below. Few women participants have associated the increasing and early onset of diabetes with change in their dietary pattern during early adult hood and adult hood. They mentioned that they did not have three meals per day earlier and hence the quantity of food consumption was less during their childhood and early adulthood. This also indirectly tells us the less (food) consumption during pregnancy period of women.

The food items which they consumed were more of small grains and millets (importantly raagi – horse millet), pulses and available green leaves such as drumstick leaves. This is reversed during the adulthood and they attributed changing food pattern / food culture to several factors and process which are gradually permeated in their lives. They are of several micro-level to macro level factors like increasing nuclear families, increasing roles for women (sharing of bread winning), culture of buying food from outside, increase of tea shops, eating outlets, increasing TASMAC, use of processed and refined food items to increasing super markets, influence of media and advertisements in buying culture, increasing small scale industries, migration, flood and famine, changes in crop pattern and food production, public distribution system and so on. This kind of explanation broadly supports Neel's and Barker's hypothesis²³.

²³Barker's hypothesis i.e. It informs us the relationship between poor nutritional status of foetus, its' development and onset of coronary artery disease, metabolic syndrome and diabetes during adult life. The poor in-utero environment has an effect on the poor development organs such as pancreas and its' effect on function of beta cells and further insulin-glucose metabolism. The changes happening during foetal development are irreparable and hence this unaltered foetal programming when combine with the later life effects such as overweight, obesity and physical inactivity increase the risk of the metabolic disorders such as diabetes.

Neel's hypothesis proposes that the genetic predisposition of insulin resistance have helped during food deprivation when the muscle utilize less glucose and supports glucose utilization by other body organs, which operate through insulin-independent mechanism. This further argues that genetic

Chart3.1: Average age at diagnosis of diabetes by caste groups



3.7.Prevalence of Complications and Co-morbid conditions: It is found that a total of 35.6% the male participants and 36.5% the female participants have one or the other complications due to diabetes such as vision problem, foot problem, cardiac problem, kidney problem, stroke, dental problem, erectile dysfunction, hyper or hypoglycaemia. It is common to note that hypertension is the most prevalent co-morbid condition among the study participants (M=24%, F=27%). It is also important to note that 19.5% of the male participants and 13.5% of the female participants have hypertension along with any one of the complications mentioned above. The prevalence of cardiac problem is slightly higher among females (6.1%) than males (3.8%) but it is not statistically significant. The presence of complications is varied significantly in terms of complications such as stroke (M = 4.8%, F = 0.0%) and kidney problem (M=2.9%, F=0.0%), conditions of hyper or hypoglycaemia and the same is represented in the Chart 3.2 below.

The respective tables 3.7 and 3.8 showing Caste and class distribution of complications are given below. It is observed that overall caste wise prevalence of complications is slightly more among MBC (42.7%) and BC (41.7%) than among SC (29.5%), BCM (33.3%) and OC (28.6%). The statistical significance is observed only in the overall prevalence of complications between MBCs and SCs and complication wise prevalence also does not varied

selection of predisposition of diabetes among population might have happened over thousand years of time, when they were better adapted to different nutritional circumstances than those experiences presently.

significantly across caste. Whereas class wise prevalence of complications has shown an increasing trend from landless labourers (33.6%) to marginal farmers (36.6%) but not varied significantly. The small and middle peasants are proportionately showing higher prevalence of complications (44.4%) from job holders or retired from government and other professionals (39.3%) and these two groups are fairly varied from the other two groups. There is no variation in the class wise distribution of the participants having hypertension with any one complication (landless labourers =15.3%, marginal farmers=14.6%, small and middle peasants = 16.7% and Job holders/retired from government and professionals – 17.9%).

Cardio vascular diseases and renal complications are found to be the main reasons for the deaths happening among diabetics (IDF, 2017). A cross sectional study conducted in 12 primary care centres in Kanchipuram district (Maniarasu K and Muthunarayanan L, 2017) has shown 32% prevalence of any one complications (excluding retinopathy). They diagnosed 19% Peripheral neuropathy, 7.8% Ischaemic Heart Disease, 30.8% Stage I kidney disease and 10.7% of Stage II or III kidney disease. They also detected 13% hypertensives newly in addition to 48% known hypertensives. This is more than double the prevalence of hypertension reported in the current study. While study conducted in rural area of western UP has shown 20.2% neuropathy, (15.3%) retinopathy and (5.6%) nephropathy. The same study has shown 38.9% hypertension and 9.1% coronary artery disease (Kumar M et al, 2016). Whereas the study conducted in rural part of Goa (Nafiza CV et al., 2011) had shown higher prevalence of neuropathy (60%).

The present study also shows no variation in the prevalence of co-morbid condition across gender, caste and class. Hypertension is the most prevalent co-morbid condition among the study participants. The prevalence of hypertension is 24% among males compared to 27% among females. It is also observed that 2% of the study participants also suffered from tuberculosis (M =7,4.8%, F= 1,0.7%) and all those who are affected with TB belong to the scheduled castes except one male belong to most backward caste and only one female who belonged to backward minority (muslim) group. Similarly the condition of thyroid is prevalent only among the female participants (N=7, 2.8%). The overall picture of Co-morbid conditions prevalent among the participants is given in the table 3.9 below. The Tables 3.10 and 3.11 representing Caste and Class distribution of co-morbid condition are given in the annexure.

While the increasing age and increasing diabetes duration has shown the gradual increase in the presence of complications and also co-morbid condition among the participants. This is well coincide with the other epidemiological studies. A study conducted in urban India had shown the higher prevalence of complications among the low income group compared to high income group. The authors attributed this high prevalence to poor glycaemic control among the low income group (Ramachandran et al, 2008). The present study has shown the high prevalence of foot ulcer among the landless and marginal labourers. The ICMR –INDIAB study had shown that risk factor for CVDs like dyslipidemia is high among females than males (Shashank RJ, 2014).

Above all, one must keep in mind that the prevalence of complication and co-morbid condition is a reported prevalence by the participants and also checked with available medical records such as laboratory reports or the individual patients' register provided by the concerned health facility. The patients would be aware of their complications mainly if they have had undergone screening for complications. As the duration increases, onset of complications will also increase.

Chart3.2: Gender wise Prevalence of Complications



Table 3.7: Caste wise prevalence of complications

Complications	SC	MBC	BCM	BC	OC
Nil	74 (70.5%)	51 (57.3%)	10 (66.7%)	21 (58.3%)	5 (71.4%)
Eye Problem	6 (5.7%)	7(8.0%)	2 (13.3%)	2 (5.6%)	0
Foot Problem	9 (8.6%)	9(10.2%)	0	8 (22.2%)	0
Cardiac Problem	3(2.9%)	4(4.5%)	1(6.7%)	5 (13.9%)	1 (14.3%)
Kidney problem	1 (1.0%)	1 (1.1%)	0	0	0
Stroke/Paralytic attack	1 (1.0%)	4 (4.5%)	0	0	0
Dental	1 (1.0%)	3 (3.4%)	1 (6.7%)	0	0
Erectile Dysfunction	1 (1.8%)	0	0	0	0
Hyper/Hypoglycaemia	6 (5.7%)	8 (9.0%)	1 (6.7%)	0	1 (14.3%)
Total presence of complications	31(29.5%)	38(42.7%)	5 (33.3%)	15 (41.7%)	2 (28.6%)
Presence of two or more complications	3 (2.9%)	2 (2.2%)	0	2 (5.6%)	0
Presence of complications with hypertension	13 (12.4%)	17 (19.1%)	2 (13.3%)	(19.4%)	1 (14.3%)

Source: Field survey, 2015-2017

Table 3.8: Class wise prevalence of complications

Complications	Landless labourers	Marginal Farmers	Small and Middle Peasants	Government job / Retired / professionals
Nil	91 (66.4%)	26 (63.4%)	10 (55.6%)	34 (60.7%)
Eye Problem	9 (6.6%)	4 (9.8%)	1 (5.6%)	3(5.4%)
Foot Problem	14 (10.2%)	1 (2.4%)	3(16.7%)	7 (12.5%)
Cardiac Problem	5 (3.3%)	3 (7.3%)	1 (5.6%)	4 (7.1%)
Kidney problem	1 (0.7%)	0	0	1 (1.8%)
Stroke/Paralytic attack	3 (2.2%)	2 (4.9%)	0	0
Dental	3 (2.2%)	1 (2.5%)	1 (5.6%)	0 (0.0%)
Erectile Dysfunction	1 (0.7%)	0	0	1 (1.8%)
Hyper/Hypoglycaemia	7 (5.1%)	3 (7.3%)	0	5 (8.9%)
Total presence of complications	46 (33.6%)	15 (36.6%)	8 (44.4%)	22 (39.3%)
Presence of two or more complications	3 (2.2%)	1 (2.4%)	2(11.1%)	1 (1.8%)
Presence of complications with hypertension	21 (15.3%)	6 (14.6%)	3 (16.7%)	10 (17.9%)

Source: Field survey, 2015-2017

Table 3.9: Prevalence of Co-morbid condition

Co-morbid condition	Male	Female	Total
Nil	66 (63.5%)	91 (61.5%)	157 (62.3%)
Hypertension	25 (24%)	40(27%)	65 (25.8%)
Thyroid	0	4 (2.7%)	4 (1.6%)
Asthma	3 (2.9%)	2 (1.4%)	5 (2.0%)
Others	3(2.9%)	6 (4.1%)	9 (3.6%)
TB	5 (4.8%)	0	5 (2.0%)
Cancer	0	1 (0.7%)	1 (0.4%)
BP and Thyroid	0	3 (2%)	3 (1.2%)
BP and TB	2 (1.9%)	1 (0.7%)	3 (1.2%)
	104 (100%)	148 (100%)	252 (100%)

Source: Field survey, 2015-2017

With an overall understanding of socio-economic and disease profile of the study participants through the quantitative survey, it is important to select the study participants for the in-depth study on the process of coping with diabetes. Hence, as mentioned in the method section, the study participants were selected by drawing a matrix (Table 3.12(a), 3.12(b), 3.12(c), 3.12(d) and 3.12(e) based on caste, class, gender and presence of complications as follows. A total of 54 participants (F = 32, M=22) were selected for the in-depth interviews to study the process of coping. The socio-economic characteristics, disease and treatment profile of the selected participants are presented caste wise one by one. Similarly, under each caste category, the information is arranged according to the class in Table 3.13.

There are 10 women selected from the Scheduled Castes and most (8) of them were landless labourers. Only 1 is a marginal farmer and another is a woman from class V as his son, an Engineer and working abroad. Two women were living with serious complications, one with uncured foot ulcer (Mrs. V) and another (Mrs. MU) with heart disease who was admitted recently in the hospital for treatment. Few (Mrs. R and Mrs. M) have experienced hyper/hypoglycaemic conditions.

Similarly, 10 men were selected for in-depth study of the process of coping. Among them, 7 were landless labourers, two were marginal farmers and one had a permanent job in the government. There were five men who experienced complications / co-morbid conditions Mr. G (kidney diseases), Mr. D (vision problem) and Mr. M (Erectile dysfunction), Mr. PO(hyperglycaemia) and Mr.PA(Tuberculosis).

Subsequently to SCs, the details about the most backward castes are as follows. There were 9 women participants, 5 from landless labourers, 2 from government job holders/retired and 1 is a marginal farmer group. Two of them having cardiac problems, one is having vision problem and other two, the condition of hyper / hypoglycaemia.

Among males from the most backward castes, 2 were landless, 2 were marginal farmers and 1 was a middle peasant. One participant had experience stroke, another had experienced stroke with cardiac problem and the other had dealt with tuberculosis.

All the 5 women from the backward class Muslims were landless labourers, one affected with cardiac problem and another got infected with tuberculosis recently. There was one man from BCMs and who was a landless labourer living with foot ulcer.

There were 6 women participants from the backward castes, 1 was a marginal farmer, 2 were from landless class, 1 was from a small peasant family and 2 others from class V (family members holding /retired from the government job). Among them, 2 women were having complications, 1 with both cardiac problem and foot problem and another with foot problem.

Comparatively there were 4 men from backward castes, 2 were landless labourers, one was a middle peasant and another was a retired teacher (class V). Among them, one was with vision problem and another with cardiac problem and treated vision problem.

There were 3 participants to represent forward castes, among 2 females, 1 was a marginal farmer and another was a middle peasant, then one male participant who was a middle peasant. Among them, one female participant was having cardiac problem.

The process of everyday coping with respect to gender, caste and class will be examined in the chapter 6.

Table 3.12 (a): Selection of study participants for the in-depth study (Scheduled caste)

Landless Labourers				Marginal Farmers				Small and Middle Peasants				Government job/ retired / professionals				Total			
M		F		M		F		M		F		M		F		M		F	
a	b	a	B	A	b	a	b	a	b	a	b	a	b	a	b	a	b	a	b
21	7	29	15	6	1	3	0	0	0	1	0	7	4	8	3	34	12	41	18
4	2	4	3	2	0	2	0	0	0	0	0	0	1	1	0	6	4	7	3

a – without complications b – with complication Participants - in-depth interviews

Table 3.12(b): Selection of study participants for the in-depth study (BC Minorities-Muslim)

Landless Labourers				Marginal Farmers				Small and Middle Peasants				Government job/ retired / professionals				Total			
M		F		M		F		M		F		M		F		M		F	
a	b	A	B	A	b	a	b	a	b	a	b	a	b	a	b	a	b	a	b
0	2	10	2	0	0	0	0	0	0	0	0	0	0	1	0	0	2	11	2
0	1	4	1	0	0	0	0	0	0	0	0	0	0	0	0	0	1	4	1

Table 3.12(c): Selection of study participants for the in-depth study (Most Backward Caste)

Landless Labourers				Marginal Farmers				Small and Middle Peasants				Government job/ retired / professionals				Total			
M		F		M		F		M		F		M		F		M		F	
a	b	A	b	A	b	a	b	a	b	a	b	a	b	a	b	a	b	a	3
9	5	13	7	4	5	9	9	3	3	1	3	7	2	5	4	23	15	28	23
2	0	2	1	1	1	2	2	0	1	0	0	1	0	0	2	4	2	4	5

Table 3.12(d): Selection of study participants for the in-depth study (Backward Caste)

Landless Labourers				Marginal Farmers				Small and Middle Peasants				Government job/ retired / professionals				Total			
M		F		M		F		M		F		M		F		M		F	
a	b	A	b	A	b	a	b	a	b	a	b	a	b	a	b	a	b	a	b
3	1	8	5	1	0	2	0	1	0	0	1	3	5	3	3	8	6	13	9
1	1	1	1	0	0	1	0	1	0	0	1	0	1	2	0	2	2	4	3

Table 3.13 (e): Selection of study participants for the in-depth study (Other Caste)

OC																			
Landless Labourers				Marginal Farmers				Small and Middle Peasants				Government job/ retired / professionals				Total			
M		F		M		F		M		F		M		F		M		F	
a	B	A	b	A	b	a	b	a	b	a	b	a	b	a	b	a	b	a	B
0	0	0	0	0	0	1	0	3	0	1	1	0	1	0	0	3	1	2	1
0	0	0	0	0	0	1	0	1	0	0	1	0	0	0	0	1	0	1	1

Table 3.13: Socio- Economic characteristics, Disease and Treatment Profile of Study Participants for the In-depth Study

Class	Caste/ Gender	Name	Socio- Economic Profile	Disease and Treatment Profile
Class I	SC/F	Mrs. RU	48 years, 8th standard, widow, living in a group house (provided by the government), depends on NREGA work (earns up to Rs. 2000) , sweeping and keeping water at an office (earns Rs. 1000) in the neighbourhood, nuclear family, living with three daughters - One married and other two - 28 and 26 years working in an export company (earning up to 4000 each),	Duration - 2 years, Compliant: giddiness, vision problem Complication: hyperglycaemia Co-morbid condition: - presently treated at: Tirukalukundram Government Hospital (GH) Medicines: Metformin, Glibenclamide and B. complex
Class I	SC/F	Mrs. M	40 years, illiterate, widow, living alone in a thatched roof, was working in a pen company, job lost due to ill health (hypoglycaemia and fainted) and currently depends only on NREGA as she could not involve in agricultural work as earlier and earns up to 2000 per month	Duration: 2 years Compliant: breathlessness Complication: hypoglycaemia Co-morbid condition: Asthmatic (depends on inhaler) presently treated at: Tirukalukundram GH Medicines: Metformin, Glibenclamide and B. complex
Class I	SC/F	Mrs. SH	41 years, illiterate, married, living in a semi-pucca house, working under NREGA / agricultural labour, having two visually challenged sons (elder one - mentally challenged). Husband would take care of a his elder son, a cow and a calf, sell cow's milk of 1 or 1 1/2 litres of milk, getting financial support of Rs.1000 from the government for each son. One son is studying in a blind school at Chennai.	Duration: - 2 years Complication: - Co-morbid condition: - Presently treated at: taking medicines at Tirukalukundram GH and taking blood test at RUWSEC hospital Medicines: Metformin, Glibenclamide and B.Complex

Class I	SC	Mrs. L	60 years, married, illiterate, pucca house, joint family (her son, daughter in law and their two children), taking care of household chores only, Husband and Son - NREGA (up to 2000 each) / daughter in law - house keeping work (earns Rs.3500 per month)	Duration - 4 years Other Compliant: - Complication : - co-morbid condition: Hypertension, Vision problem, presently treated at: RUWSEC (clinic run by NGO) medicines: Amlodipine, Atenlol, Glibenclamide, Metformin (Husband - Diabetic, hypertensive and had a paralytic attack recently)
Class I	SC	Mrs. R	38 years, Illiterate, married, pucca house, Nuclear family, NREGA / agricultural labour – earns around Rs.3000 per month, Husband - Agriculture / construction coolie worker(used to earn around 400 per day and would give family ra.100 or Rs. 200 per day), Son - 10th std - irregular employment, daughter - 12th std - export company (earns Rs.6000)	Diabetes - 3 years Complications: - Co-morbid condition: Other compliant: tiredness Presently treated at: RUWSEC Medicines: Metformin, glibenclamide
Class I	SC	Mrs. MU	42 years, no formal education, married, semi-pucca house, Nuclear family, NREGA - 1500 to 1800rs, Husband - Coolie - 20 days work - 300 to 400 per day Son - studying 10th standard Was living in a pucca house (group house, now the roof which is a cement concrete falling down gradually due to its' poor strength)	Diabetes - 13 years Complication: Cardiac problem Co-morbid condition: BP Other Compliant: Blurred vision Presently treated at: CMCH and also at Private hospital Medicines: Biphasic Isophane (30% soluble insulin and 70% isophane insulin), clopidogrel, metolar, dampaidine, aspirin, diaba care (siddha product) Family History - Mother

Class II	SC	Mrs. M. K	Age: 57 years, received no formal education, married, rearing cows and NREGA , having half acre of land (used to cultivate cow feed) Type of House: Group house Other family members : living with husband (working in a horticulture farm, daughter (working in a horticulture farm), grandson, grandson's wife and great grand son	Duration: 22 years Compliant: foot problem(burning), right hand pain Complication: - Co-morbidity: - Presently treated at: Tirukalukundram GH details of medicines: Glipizide, Metformin and B. complex fasting: 155 mg/dl post prandial: 327 mg/dl
Class II	SC	Mrs. E. AL	40 years, studied up to 8th standard, married, works under NREGA, works in farm (acre of agricultural land), also involves in chit business, pucca house, joint family, mother in law, husband (farming ad also rearing cows), 2 sons (1 completed engineering, could not get a job and another studying B.E), 1 daughter (studying B.Sc nursing)	Duration: 2 years complication: - Co-morbid condition: - Other compliant: - presently treated at: private clinic (non-profit) Medicines: metformin, daonil, b. complex and was taking kasayamm of guava leaves fasting: 173 mg/dl post prandial: 238mg/dl
Class V	SC	Mrs. SU	52 years, married, 8 th standard, pucca house, joint family, NREGA work (Rs. 1800), Resource team member (up to Rs. 500), Husband - agricultural labourer (work only for 10 or 15 days in a month, used to spend his income on alcohol), Daughter (separated) – working in a company (earns Rs. 5000 per month) and her two sons – studying in 11 th and 8 th standard respectively Son completed BE and working abroad	Duration: 3 years Complication: - Co-morbidity : BP Other Compliant: - Presently treated at: a private Medical college and Hospital (part of camp- free of cost) Medicines: Metformin, glimipride, amlong, neurobion forte Fasting: 140mg/dl, Post prandial: 230mg/dl

Class V	BC (married to SC)	Mrs. S. N	29 years, a re-married widow, studied up to 9th standard, works under NREGA, pucca house, joint family, living with husband (working as a clerk at kalpakkam atomic power station) , daughter (studying 5th standard) , mother - in law, two brother in laws (1 - working as a scientist at kalpakkam atomic power station and another as a police constable)	Duration: 1 year presently treated at : a private hospital (CGHS), Medicines: was on metformin for few months and then lifestyle modification fasting blood sugar : 96 mg/dl
Class I	SC	Mr. V.S	44 years, married, studied 10th standard, working as a Lorry driver (20 days in a month earns around Rs. 15000), pucca house Other family members : wife (NREGA) and daughter (studying 9 th standard)	Duration: 4 years Compliant: nil Complications: nil Co-morbidity: nil Presently treated at: Tirukalukundram GH, Public details of medicines: metformin, glipizide, b.complex Fasting blood sugar: 180mg/dl Post prandial : 398 mg/dl
Class I	SC	Mr. MM	Male, 45years, married, studied 5th standard, doing agriculture (tenant of 3 acres), pucca house, nuclear family, living with wife (agriculture and NREGA) and 1 son (studying 10 th standard)	Duration: 7 years Complications: Erectile dysfunction Co-morbid condition: Other Compliant: - Presently treated at: PHC and RUWSEC Medicines: Metformin, Glibenclamide and B.complex
Class I	SC	Mr. PA	Male, 46 years, married, 9th standard, working as a driver in the coal mines (Rs. 1500 for whole day and night), pucca house, nuclear family living with wife (NREGA / cow rearing), two sons (studying in 11 th and 9 th respectively)	diabetes -7 years compliant:- Complication: - Co-morbid condition: TB (recently treated at CMCH) presently treated at: RUWSEC Medicines: he was on insulin till he got cured with TB and

				currently taking metformin, Glibenclamide and B. complex
Class I	SC	Mr. A.E	58years, married, studied 5th standard, NREGA / Any other labour, pucca, joint family, living with wife (cook at a government school) and sister in law(physically challenged)	Duration: 6 years Other Compliant: - Complications: Co-morbid condition: Presently treated at: discontinued treatment from Nerumbur Primary Health Centre (PHC) Medicines: home remedy(fenugreek) only
Class II	SC	Mr. VS	40years, studied M.A., Diploma in Siddha, married, doing agriculture (1 acre of land), running a petty shop and practice siddha medicine sometimes, involved in retail business earlier, pucca house, nuclear family, living with wife (works under NREGA, agriculture)	Duration: 5 years Complication:_ Co-morbid condition: - other Compliant: - gall bladder stone Presently treated at: RUWSEC and self medication Medicines: Siddha (kasayam of keelanelli - early morning every day)
Class I	SC	Mrs. V	45 years, 8 th standard, married, living in a kacha house, nuclear family, doing household chores only, living with husband (lorry driver, used to work for 15 to 20 days and earn around 15000) per month and younger daughter (studying in college) Elder son and elder daughter – married and settled with their family in neighbouring town	duration – 7 years compliant: - Co-morbid condition:- complications: Foot ulcer – uncured for more than 3 years presently treated at: discontinued treatment from the private clinic Medicines: home remedy (taking bitter gourd juice twice or thrice in a week) Fasting: 252 mg/dl Post prandial: 408 mg/dl
Class I	SC	Mr. A. G	58 years, married, 8th standard, not working, Kacha house, living with wife (NREGA / any other work such as agriculture labour/construction	Duration: 15 Compliant: - Complication: Kidney problem / on hemo-dialysis Co-morbid condition: BP

			labour) 3 Children - 1 daughter and two sons are married and settled in the same village. he did not get any support from his children and wife is the only person taking care of him and his treatment	Presently treated at: chettinad hospital (using government health insurance) Medicines: calcium lactate, amlodipine, frusemide, ranitidine, iron and folic acid tablets, amaryl 1 mg
Class I	SC	Mrs. SA	58 years, received no formal education, married, works under NREGA, Kacha house, nuclear family, living with Husband (construction coolie worker and earns around 300 per day, used to work for 10 to 15 days in a month) , first son got married and live with his wife separately but she only used to take care of both the grandparents and second son (tempo driver)	Duration - 2 years, Compliant: - Complication: treated for foot ulcer Co-morbid condition: BP Medicine: Metformin, Glibenclamide, Enalpril Fasting: 1336mg/dl Post prandial: 180mg/dl
Class I	MBC	Mrs. D.S	43 years, received no formal education, NREGA / Agricultural coolie, Kacha house, nuclear family, living with husband (agricultural labour - 10 to 15 days and earns around 300 per day) , two sons (working in companies earns 10000 and 8000 respectively) 1 daughter got married and settled	duration: 3 years complication: co- morbid condition: - other compliant: presently treated at: both PHC and at a private clinic medicines: dibizide(1-0-0), metformin glycomet(0-0-1/2), neurobion forte fasting: 138mg/dl post prandial: 203mg/dl

Class V	MBC	R. S	49 years, studied up to 5 th standard, works under NREGA (earns up to Rs. 1800), pucca house, nuclear family, living with husband (selling rings at mahaballipuram and earns around 300 to 400 per day) and younger daughter (working in accounts of a diamond shop and earns around 15000) elder daughter got married and settled	Duration: 4 years complication: - Co-morbid condition: - Other Compliant: - Presently treated at: RUWSEC, NGO Medicines: Metformin, B. complex fasting/ PP:
Class III	BC	Mrs. K	65 years, studied up to 6 th standard, married, house wife joint family (living with husband(help in grazing cows/sheeps) , Son (agriculture / rearing cows/sheeps) , daughter in law(agriculture) , 1 grand daughter (studying 9 th standard) and a rand son (studying 5 th standard), constructing a new a house (pucca), 4 acres of wet land	Diabetes – 35 years, Complications: foot ulcer / cardiac problem (underwent cardiac surgery later a year after interview) Presently treated at: private hospital Co-morbid condition: BP Medicines: Glyciphage, PPGO3, Atorvastatin Compliant: leg pain / back pain (she used to bend and walk, could not stand straight)
Class II	MBC	Mrs. P.SA	56 years, studied up to 5 th standard, married, pucca house, Nuclear family, living with her husband and son, NREGA : yes, 55 days in 2 years Husband do farming with 2 acres of land and her son keeping a electrical shop in neighbour town and also work in farming	Diabetes - 6 years Complications: Co-morbidity: BP, high cholesterol Other complaint: gall bladder stone (recently underwent surgery for the same) Presently treated at: Nerumbur PHC Medicines: metformin, glibenclamide and B. complex
Class IV	MBC	Mr. MU	57years, married, studied up to 4 th standard, doing agriculture (7 acres of land), Kacha / (lives closer to their agricultural field),	Duration: 10 years Compliant: burning sensation in thigh region Complications: Paralytic

			<p>nuclear family, living with wife (panchayat president)</p> <p>Daughter is married and settled</p>	<p>attack</p> <p>Co-morbid condition: BP</p> <p>Presently treated at: private multispecialty hospital</p> <p>details of medicines: H. Mixtard 30/70 (10-0-8) actrapid 10-0-5 Mandtrid 15-0-10</p> <p>5 months back to survey, he was admitted in the hospital for mild CVA</p> <p>Last Blood sugar level – fasing 140mm/hg/ PP-200 mm/hg</p> <p>Other family members : Father</p>
Class II	MBC	Mr. N.S.	<p>73years, studied up to 5th standard, married, agriculture (1 acre of land - his brothers would cultivate in his land and give his share), nuclear family, living with his wife (works under NREGA, agriculture)</p> <p>Two sons and two daughters - married and settled in other towns and cities. They would visit and help only when he would fall sick or any ceremony.</p>	<p>Duration: 8 years</p> <p>Complication: PVD, hyper/hypoglycaemia</p> <p>Co-morbid condition: -</p> <p>other Compliant: -</p> <p>Presently treated at: Tirukalukundram GH and Chengalpet Medical College and Hospital (CMCH)</p> <p>Medicines: metformin, glipizide and BCT</p>
Class II	MBC	Mrs.MA	<p>40 years, married, studied up to 5th standard, involved in NREGA and also has own agriculture (2 acres of land), living in a pucca with her husband (agriculture) and Son (studying engineering)</p>	<p>Diabetes: 5 years</p> <p>Compliant: -</p> <p>Complications: -</p> <p>Co-morbid condition: -</p> <p>Presently treated at: RUWSEC</p> <p>details of medicines: metformin, glibenclamide</p>
Class II	MBC	Mr. V. S	<p>53 years, married, 2nd standard, involved in Agriculture / tractor - 2 acres /3 cows, living in a nuclear family in a pucca house with his wife and son</p>	<p>Diabetes: 7 years</p> <p>Compliant: -</p> <p>Complications: -</p> <p>Co-morbidity: -</p> <p>Presently treated at: was taking allopathy at a private clinic, discontinued</p>

				treatment presently details of medicines: glyciphage wife is also a diabetic
Class II	MBC	Mrs. SA	Age: 56 years Marital status: Married Education: 5 NREGA : nil Occupation: Agriculture Type of House: Pucca Other family members :	Diabetes: 6 years Compliant: recurrent foot infection Complications: foot infection and toe amputation Co-morbid condition: - Presently treated at: private hospital details of medicines: since 6 months - folk (herbal) medicine
Class V	MBC	Mrs. P	65 years, widow, studied 3 rd standard, living in a pucca house, joint family Occupation: nil son - son doing agriculture daughter in law - Anganwadi worker granddaughter and grandson – both are studying in school	Duration: 10 years Compliant: Complications: CAHD, blurred vision Co-morbidity: SHT, CAHD, old ASMI Presently treated at: CMCH details of medicines: metformin, glibenclamide, isosorbide dinitrate, Enalapril, Atorvastatin, Amlodipine, clopidogrel, diltazen Blood sugar level - fasting - 70mm/hg / PP - 129 mm/hg Doctor advised to go for cataract surgery and she could not go as nobody accompanying her. Her relative who used to visit to CMCH for her diabetic condition used to buy her medicines too by requesting the staff there.
Class I	BC	Mrs. K. R	38 years, married, studied up to 10 th standard, house wife, pucca house on rent, living in a joint family : mother, brothers, husband and daughter	Diabetes: 4 years Compliant: physically challenged Complications: Co-morbidity:

			<p>Elder brother and husband :Barbar shop Younger brother –driver - travel tempo Mother – NREGA Daughter – 3 years attending Anganwadi centre</p>	<p>Presently treated at: PHC and NGO details of medicines: metformin, calcium, B.complex</p> <p>Family History: Father died of diabetes and kidney disease</p>
Class I	MBC	Mrs. V. K	<p>42 years, married, received no formal education, Agricultural coolie/ NREGA, Pucca house, nuclear family, living with husband, 3 daughters - one has completed D.T.Ed and working in a private school and fourth one is a speech and hearing impaired one and did not attend school at all. The last daughter is studying in college. First two got married and settled</p>	<p>Diabetes: 3 years Complication: - Co-morbidity: - Other Compliant: fatigue Presently treated at: TKM GH Medicines: Metformin, Glibenclamide and B. complex Husband is diabetic for 10 years and he takes treatment at a private clinic and takes vobit and regular in monitoring blood glucose</p>
Class V	SC	Mr. D	<p>45 years, studied up to 10th standard, pucca house, married, working as hospital servant (permanent position at a government hospital) and earns around Rs. 17000/month Other family members : wife, two sons (studying 11th and 10th standard) and daughter (studying 8th standard)</p> <p>(As his village is very far from the work place, he used to stay at his work place only and visits home during weekends)</p>	<p>Diabetes: 3 years Complications: vision problem Co-morbidity: BP Presently treated at: GH details of medicines: metformin, amlodipine, glibenclamide and B. complex</p> <p>Fasting blood sugar - 124mg/dl Postprandial blood glucose - 140mg/dl</p>
Class V	BC	Mr. SH	<p>71 years, married, studied up to old SSLC, Primary school teacher (retired) and getting pension of Rs. 20,000, pucca house, nuclear family living with wife</p> <p>1 son and 2 daughters (all married and settled in district or state headquarters)</p>	<p>Diabetes: 10 years Compliant: shoulder pain Complications: cardiac problem Co-morbidity: BP Presently treated at: National Institute of Siddha and a Private speciality hospital Medicines: obit, glynase and siddha medicine recently undergone cataract</p>

				surgery (insurance) Other family members : wife and Son are having diabetes
Class II	BC	Mrs. AD	Female, 36 years, studied up to 8 th standard, married, pucca house, owns agricultural land (2 acres) and works under NREGA and does tailoring when she is relatively free joint family, living with husband (involve in agriculture and also earns Rs. 100 to 300 per day through coconut selling) , 1 son (studying 6 th standard) and 1 daughter (studying 8 th standard) , father-in-law and mother- in- law (works with them during their farming otherwise work under NREGA)	Diabetes: 6 years Compliant: - Complications: - Co-morbid condition: BP Presently treated at: PHC and private speciality hospital Medicines: metformin, glibenclamide, b.complex
Class II	BC	Mr. A	67 years, married, studied 9th standard, coolie (lifting vegetable bags) in the vegetable market, pucca house, joint family, wife (NREGA and cow rearing), mother in law (NREGA), daughter (NREGA), son-in –law (agriculture), granddaughter (studying 10 th standard) and grandson (studying 7 th standard)	Diabetes: 2 years Complications: - Co-morbidity: - Other Compliant: leg pain Presently treated at: Nerumbur PHC, discontinued details of medicines: -
Class I	MBC	Mr. PJ	Age: 42 years, studied up to 5 th standard, married, he was involved retail business and presently running a petty shop and earns around 150 to 500 per day, Living in a rented pucca house (Rs. 1500) Nuclear family, living with wife (house wife and also take care of petty shop when he goes out for other work) and daughter (studying 9 th standard)	Diabetes: 2 years Compliant: - Complications: - Co-morbidity: - Presently treated at: PHC, irregular treatment Medicines: Metformin, Glibenclamide and b. Complex

Class I	MBC	Mr. S.M	48 years, married, studied 10th standard, was working and earning around 8000 per month(filter/exhaust line cleaning at kalpakkam - on contract), Pucca, nuclear family, living with wife (working under NREGA), elder Son (D.C.E, works in a private concern and earns around 10000) and younger son(studying DCE)	Diabetes: 1 year Other Compliant: Complications: Co-morbidity: Presently treated at: details of medicines:H. mixtard 7-0-5
Class I	SC	Mr. PO	Male, 41 years, studied up to 8th standard, married, working as a daily wage labour for a shamiana (ceremonial tent) service, earns around Rs. 300 to Rs. 400 per day and he would get this work minimum for 10 to 15 days in a month and maximum for 20 to 25 days during festive months. He used to get agricultural coolie work for few days. wife - NREGA and Agricultural labour, two sons (studying 7 th and 5 th standard respectively)	Diabetes: 2.5 years compliant: hemoptysis Complication: _ Co-morbid condition: _ Presently treated at: Chengalpet Medical College and Hospital Medicines: Actrapid 10-0-5 Mandtrid 15-0-10 Fasting : 218 mg/dl Post prandial: 293 mg/dl
Class I	SC	Mr. V	31 years, married, 5th standard working as a cook at a private company and earns Rs. 10000, pucca house, joint family, living with mother (sheep rearing) , wife (NREGA), 1 daughter (3 years) and 1 son (1 year)	Diabetes: 1 year Complications: - Co-morbid condition: Other Compliant: - Presently treated at: RUWSEC Medicines: metformin, glibenclamide, b.complex Random blood sugar: 170mg/dl
Class I	BCM	Mr. SF	Age: 48years, studied up to 5th standard, married, selling aluminium utensils and earns around Rs. 300 to Rs. 400 per day), pucca house, joint family, living with two wives (1- working in an export company - Rs. 4500 and another works under	Diabetes: 5 years Complications: foot ulcer Co-morbid condition: - Other Compliant: - Presently treated at: discontinued Medicines: Home remedy

			NREGA work - Rs. 1800) , 2 sons (discontinued school education from 12th and 10th and involved in religious activities in nearby mosque) and 2 daughters (1 completed 12th standard and the other studying 6th standard)	(kasayam of nithyakalyani root)
Class I	BCM	Mrs. MB	39years, studied up to 5th standard, married, works under NREGA (was doing beedi rolling and presently left it because of health condition), joint family, living with her husband (tailor) son (auto driver), daughter in law (house hold work and a granddaughter (7 months old)	Diabetes: 6 years Complication: - Co-morbid condition: PTB other Compliant: - Presently treated at: TKM GH and CMCH Medicines: metformin, glibenclamide and BCT, (was on insulin and ATT when treated for TB)
Class I	BCM	Mrs. PB	57 years, widow, received no formal education, works under NREGA, thatched house, living alone, two sons - married and settled in another town	Diabetes: 5 years Complication: Co-morbid condition: hypercholesterolemia Other Compliant: vision problem (long sightedness) Presently treated at: TKM GH Medicines: glibenclamide, metformin, bcomplex, Atorvastatin Fasting: 96 mg/dl Postprandial: 193 mg/dl Family History: Brother
Class I	BCM	Mrs. M. M	37years, studied up to 5th standard, married, works under NREGA and also doing beedi rolling joint family, living with her mother (helps in household chores) husband (cycle repair) daughter (studied up to 12th standard, takes care of household chores)	Diabetes: 8 years Complication: - Co-morbid condition: BP, high cholesterol other Compliant: - Presently treated at: TKM GH and CMCH Medicines: metformin, amlodipine and rosuvastatin
Class I	BCM	Mrs. R B	60 years, studied up to 3rd standard, widow, works under NREGA (up to Rs. 1800 per month) and also doing beedi rolling (Rs.1500) , pucca house, living alone Son is married and settled in	Diabetes: 5 years Complication: cardiac problem Co-morbid condition: BP other Compliant: - Presently treated at: TKM GH Medicines: metformin,

			another town	glibenclamide, b.complex, Amlodipine, atorvastatin
Class I	BCM	Mrs. K	35 years, received no formal education, married, household chores, nuclear family, pucca house, living with husband (tailor) and a daughter (adopted) – studying LKG	Diabetes: 3 years Complication: - Co-morbid condition: - other Compliant: itching all over body Presently treated at: TKM GH and RUWSEC Medicines: metformin, glibenclamide, b.complex fasting - 141mg/dl and post prandial - 208mg/dl
Class I	BC	Mrs. S. M	63years, 7th standard, widow, NREGA (up to Rs.1800) given shops for rent and earns around Rs. 1500, household chores, pucca house, living alone two sons are married and living in the neighbourhood separately	Diabetes: 4years Complication: foot ulcer Co-morbid condition: BP other Compliant: Presently treated at: Nerumbur PHC and RUWSEC Medicines: daonil, metformin, envas, B complex and aloe vera juice fasting - 88 mg/dl and post prandial - 223mg/dl
Class I	BC	Mr. M. S	42years, studied up to 10 th standard, married, doing agriculture (1 acre of land) and working as a cashier in a petrol bank (10000), pucca house, nuclear family, living with wife (helps in agriculture and rearing cows), 1 daughter (studying 12th standard) and 1 son (studying 10th standard)	Diabetes: 2years Compliant: - Complications: Co-morbid condition: BP started Presently treated at: private clinic Medicines: glynase / not taking medicine for BP
Class IV	BC	Mr. R. R	56years, studied up to 5th standard, widower, agriculture (7 acres of land) and doing rice business, earns around Rs. 400 to 500 in a day depends on the business), pucca house, living alone (wife (2014) and daughter (2016) were died of diabetes and kidney diseases)	Diabetes: 2years Compliant:- Complications: Co-morbid condition: BP Presently treated at: PHC, Nerumbur Medicines: metformin, glibenclamide and amlodipine fasting - 96 mg/dl and post prandial - 138 mg/d

Class IV	OC	Mr. R.V	55years, studied up to 9th standard, married, agriculture (7 acres of land), was former panchayat president, pucca house, joint family, living with father, wife (house wife) and daughter (studying college)	Diabetes: 3 years Other Compliant: - Complication: Co-morbid condition: BP Presently treated at: private clinic Medicines: Amlong, Glyciphage, Metformin fasting - 131 mg/dl and post prandial - 269 mg/dl other family member: mother
Class II	MBC	Mrs. A. K	53years, received no formal education, married, works under NREGA / sometimes take care of cows, pucca house, nuclear family, living with her husband (agriculture (1 acre of land/ grazing cows) and son (tailoring and agriculture)	Diabetes: 1 year Other Compliant: hepatomegaly, severe fatty liver Complication: dental problem Co-morbid condition: high cholesterol Presently treated at: private clinic and RUWSEC (NGO) Medicines: telmasartan, omeprazole, rosuvastatin, glyciphage metformin fasting - 134 mg/dl and post prandial - 182 mg/dl other family member: parents and siblings and one brother died of ESRD
Class IV	OC	R. K	52years, studied up to 5th standard, married, agriculture (10 acres of land - left on contract and getting their share from the tenants), pucca house, nuclear family, living with her husband (and daughter (widow) Second daughter is married and settled in the state head quarters	Diabetes: 7years Compliant: Complication: cardiac problem Co-morbid condition: BP, thyroid Presently treated at: private speciality hospital and RUWSEC (NGO) Medicines: _____ fasting - 139 mg/dl and post prandial - 156 mg/dl other family member: both father and brother died of ESRD

Class II	OC	S. UM	36years, studied up to 12th standard , married, agriculture (2acres of land / rearing cows / tailoring) , pucca house, nuclear family, living with her husband (works with his father-in- law in Chennai at mechanic shop and earns around 10000 and he would visit her during weekends only (and daughter (living in her grandparent's house, studying college)	Diabetes: 9years Compliant: Complication: cardiac problem Co-morbid condition: BP, thyroid Presently treated at: private hospital and and RUWSEC (NGO) Medicines: glibenclamide and metformin fasting - 190 mg/dl and post prandial - 280 mg/dl other family members: paternal grandmother and her daughter
Class I	BC	V. T	65 years, married, studied up to 8th standard, was selling vegetables at chengalpet and presently he could not go because of his vision problem, trying to get NREGA card (they shifted to the village recently from the district head quarters), pucca house, nuclear family, living with his wife(house wife) and a daughter (works in a pen company and earns around 5000 per month)	Diabetes: 2 years complication: vision problem (cataract), high sugar (could not control to undergo cataract surgery) Co-morbid condition: - Other compliant: presently treated at: PHC Medicines: metformin, b.complex and also taking 'kasayam of nithyakalyani' fating: 180 mg/dl post prandial: 258mg/dl
Class V	BC	Mrs. C	48 years, married, studied up to 8th standard, house wife, pucca house, nuclear family, living with husband (retired VAO and getting pension of Rs. 12000), son (B.E, working in a private company and earns around 15000) and a daughter studying 12th standard elder daughter got married and settled in state head quarters	Diabetes: 11 years Complication: Co-morbid condition: BP, Hypercholesterolemia other compliant: indigestion, had undergone appendicitis surgery (government insurance scheme) presently treated at: private clinic and sometimes used to visit specialty hospital for master check up Fasting blood sugar: 308 mg/dl

CHAPTER 4

Experience of Symptoms and Process of Treatment Seeking Behaviour

4.1. Concept of illness and conceptual framework in studying illness behaviour

The state of health and illness differs from individual to individual based on their perception, knowledge, experience of symptoms, their severity and the illness. Several scholars who have contributed to some important terms and concepts have studied few or more aspects on this subject. To mention a few, “special position of the sick” (Sigerist, 1929; 1960 in Young TH, 2004), “sick role” by Parsons T (1951) and later Mechanic D and Volkart in 1961 had introduced the concept of “illness behaviour” as “the way in which symptoms are perceived, evaluated and acted upon by a person who recognizes some pain, discomfort, or other signs of organic malfunction” (pp.87).

Suchman E (1963; 1965) formulated an approach to study the illness behaviour which constitute five “stages of illness”: 1) symptom experience, 2) assumption of the sick role, 4) dependent-patient roles and 5) recovery and rehabilitation”(pp.67-68). This approach draws more from social psychology and social anthropology. Zola IK (1965) illustrated the patterns of experiences of nature and type of symptoms and variations across different social groups. This work brought out more of socio-cultural aspects of the illness behaviour. Mechanic’s work was drawn from medicine and behavioural sciences and was more of medical sociology in nature. Despite different approaches and methods, works by all these three authors complement one another. It contributes to a comprehensive understanding for studying illness behaviour.

When someone feels the discomfort, the individual may try to accommodate that uneasy subjective experience to some extent at the individual level. When the symptoms are unusual, become recurrent and persistent and intolerable, then it is an important step for treatment seeking. When the intensity of symptoms disrupts the daily activity and affects the social roles and responsibilities, then the individual starts assuming the sick role and seeks treatment. The individual often shares the illness experience with a family member, neighbour or a friend who provides support and advice where to go for treatment. This process is called as ‘**social comparison**’ (Festinger, 1954 in Radley A, 1994). This is also explained as process of socialization in illness behaviour in Mechanic’s ‘**Social Construction of illness**’. Mechanic’s work over a period of time had identified 10 different determinants in response to illness and these include the following.

“1) The visibility, recognisability, or perceptual salience of symptoms, 2) The perceived seriousness of symptoms, 3) The extent to which symptoms disrupt family, work and other social activities, 4) The frequency of appearance of symptoms, their persistence or frequency

of recurrence, 5) The tolerance threshold of those who are exposed to and evaluate the deviant signs and symptoms, 6) Available information, knowledge, cultural assumptions and understandings of the evaluator, 7) Perceptual needs that lead to autistic psychological process, 8) Needs that compete with illness response, 9) possible interpretations that can be assigned to the symptoms once they are recognized and 10) Physical proximity to treatment resources and psychological and monetary costs of taking action (which includes the cultural and social accessibility of the provider)”(Mechanic D 1968 in Weiss Gregory L 1994 pp.132-133).

Some of these ideas resonate with the conceptualisation of various levels of awareness of symptoms for treatment seeking by Banerji and Anderson (1963). When an individual perceives the symptom or symptoms, one might feel bodily discomfort and this state they labelled as ‘mere consciousness’. When symptoms get intense it may make the individual worry for the persistence of the symptoms, which they called as ‘worry awareness’. Then later when symptoms get severe, the individual who suffers from it moves into next level of awareness. At this level the individual is driven to seek treatment in order to alleviate the symptoms and is termed as ‘action taken’.

The treatment seeking, continuity of treatment and curing the disease condition (tuberculosis) by the individual is also dependent on the availability and responsiveness of the health services and its ability to provide relief from the symptoms experienced, which can be also called ‘felt needs’ of the individual. The authors, by delineating the levels of awareness and action, have demonstrated that the social dimensions of treatment seeking go beyond the pathological aspect and include the psychological, economic, social and institutional (health care services) factors.

This social approach gives credibility to the subjective experiences at the individual level and the interaction with the health services. This kind of interdisciplinary investigation had thrown a possibility of identifying the individuals affected with TB by relying on symptom experiences. Thus, symptom experience is the starting point of the Tuberculosis programme, which is backed up by a sputum test instead of conducting mass screening programmes for tuberculosis. The socio-economic position of the individual and his/her interaction with the family and further the community is sparsely addressed in this study.

Extending the scholarly work of Mechanic (1961;1969), Banerji and Anderson (1963), Zola I (1964) and Suchman(1965), Baru RV (2005) argues that ‘symptom of a disease was an important point for predicting response to illnesses and therefore the pattern of health seeking behaviour was shaped by the severity of symptoms, its persistence and its perceived threat to individuals’ (pp.46-47). In addition, health seeking behaviour is not only influenced by the severity of the symptoms as the illness is not only of physical or physiological or pathological aspect but also includes several other aspects and layers such as emotional(psychological), social and economic level which are interacting with each other. When one tends to recognize the symptoms, it dislocates the individual through one or more of these levels and which also interacts with each other before or during health seeking. She tried to explain this complex interaction in health seeking behaviour by taking the case of persons suffering from AIDS.

The previous study by the researcher (Arutselvi, 2013) had attempted to look into this aspect of the social and living condition of the individual and intra-household dynamics and community interaction in the process of treatment seeking for diabetes among the individuals in urban Chennai. It observed that it is not only the severity of the symptoms that influences treatment seeking behaviour. The study showed that the socio-economic position of the individual also plays an important role in treatment seeking behaviour. It found that the level of tolerance by the individual and disruption of daily life in performing daily routines or becoming physically inactive too determine the treatment seeking behaviour. This is what Herzlich (1973 in Radley A, 1994) called as ‘experiential aspect’.

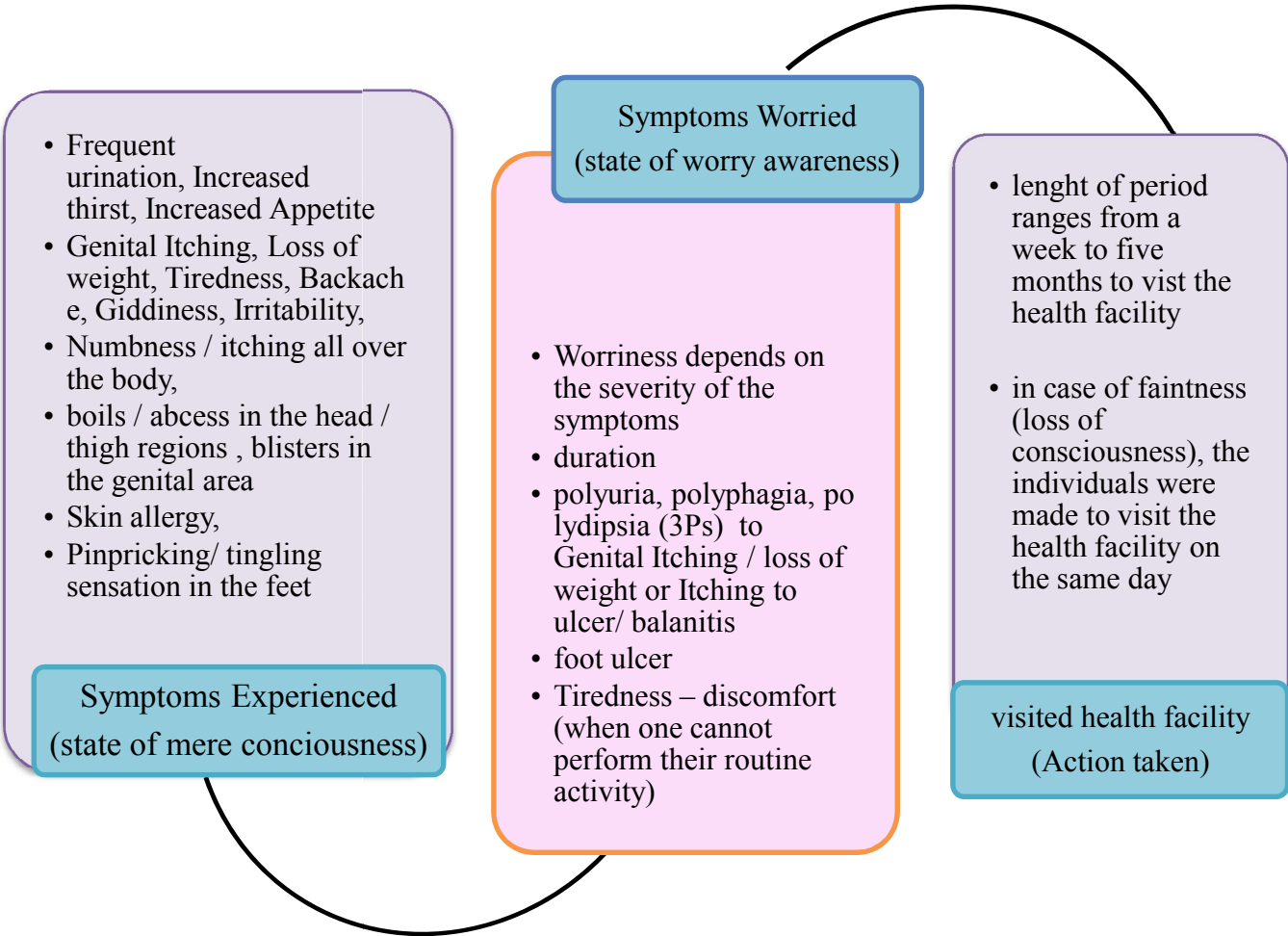
Bodily symptoms make individuals take action for relief. But the length of time taken to seek treatment differs from one person to another. Severity of symptoms was an important determinant to visit the health facility. For example, when a person experienced a mild genital itching, she might try to heal with some home remedy first. Later, when she could not tolerate the discomfort with the symptoms becoming severe (ulcer in the genital area due to itching) a visit the health facility would be made immediately. Consider a second person who experienced a mild genital itching for few days, then disappeared and later re-occurred. Here the recurrence of symptoms might or might not lead to her visiting the health facility as she might tolerate the discomfort caused by mild genital itching. But in the first case, the symptom worsened even after trying the home remedy and which made her visit the health facility immediately.

This present study has tried to look into the process of symptom experiences and treatment seeking of diabetes among individuals living in a rural area of Kanchipuram district of Tamil Nadu. A broader framework like Banerji and Anderson (1963) is considered suitable in studying the symptom experiences of diabetes too.

4.2. Level of awareness of symptoms and treatment seeking in diagnosis of diabetes

The common pattern which is seen among the individuals in perceiving and experiencing the symptoms is represented in the figure 4.1

Figure 4.1



It is found that about 76.6% of the study participants (Total-252: M-104, F-148) experienced one or more of the classical symptoms, such as polyuria (frequent urination), polydipsia (frequent thirst) and polyphagia (frequent hunger). They also had other symptoms such as feeling of tiredness/dizziness/giddiness which they expressed as ‘feel like lying in bed all the time’ / ‘not feeling to wake up from the bed’, ‘feeling like I do not have energy in my body’,

feeling sleepy/lazy, and presence of abscess/boils/blisters/tumours in head or thigh / feet region, ulcers in the feet, itching in the genital area, loss of weight, loss of weight, fever, and infections such as RTI.

In the remaining 24.4%, 7.1% of the study participants were diagnosed with diabetes when they had experienced some other illness. It is important to look into the participants who were diagnosed with diabetes when they were getting treatment for some other illness. Because once the individual becomes diabetic, he or she needs to reduce the sugar level to perform procedures such as removal of tumour or a cataract surgery. This remained as a challenging task for them, more discussion on this will follow in forthcoming sections. Few other conditions for which the participants got treated were gall bladder stone, hysterectomy, kidney stones, recurrent fever and other persistent infections. Around 9% of the participants had a chance of attending a screening camp for diabetes conducted either by the private Non-profit organisations or public health care facility. A small percentage (3%) were diagnosed with diabetes when they were pregnant (gestational diabetes) and continuing medicines (oral hypoglycaemic agents or insulin) as the blood sugar was not back to normal after the delivery. The details of how people detect and came to know about diabetes are given in the table 4.1.

Table 4.1: Detection of diabetes

Detection of diabetes	Number of participants (%)
persistent symptoms related to diabetes	193 (76.6%)
some other illness	18 (7.1)
Faintness (stage of unconsciousness)	8(3.2)
Camp	23 (9.1)
Gestational diabetes	4 (1.6)
Routine check up	6 (2.4)

Source: Field Survey, 2015-2017

There are some other instances that made individuals seek treatment immediately. These included fainting and sudden unconsciousness. Around 3% of the participants experienced faintness and visited the health facility sooner.

4.3. Intensity of symptoms and disruption of daily lives

Spells of tiredness were found to be common among most of the participants.”Always I am feeling tired” “I am feeling weak”, “feel like lay down forever” “whether someone would help me in cooking?, fetching water?”, “a kind of dependency gradually occupies me” “don’t feel like waking up in the morning”, “never postponed any work but postponing things” are the common phrases expressed by them (Interviews conducted in the villages of Tirukalukundram block, 2015-2017).

The perception of the symptoms is the first step in treatment seeking as the individual needs to be aware of the bodily discomfort. The perception of symptoms also depends on the knowledge about symptoms, duration and severity of the symptoms experienced, previous experience of illness or close observation of illness experience by a family member or a close friend or a relative. Then this process continues with worrying about the symptom. The state of being worried seemed to be felt among the participants when the symptoms persist for a longer period of time. The state of ‘worry awareness’ will last only for a day or few days in case of classical symptoms whereas it will still last for few weeks if they have experienced tiredness only. People tend to take the next step when they experience drastic changes in the body i.e. persisting bodily discomfort with multiple symptoms. For instance when someone notices sudden loss of weight, faintness, genital itching or ulcer in the genital area, and other indications of intensifying symptoms, the affected individual will start worrying about the symptoms that influence the individual to seek treatment from the available health care resources.

The ‘action taken’ occurs gradually when individuals experience the persistence of symptoms listed above. Based on the duration and intensity of the symptoms that may persist over few days to few weeks and even months will determine when the individual takes action.

There are instances when individuals who have experienced symptoms for more than a year but have not have been diagnosed with diabetes. For example, Mrs. M, 40 years old, from most backward caste shared that she was experiencing skin problem (padai) for more than six months. Initially she had experienced itching (redness) of the skin at one or two places on her leg and hand for almost a week. She had applied coconut oil first. But she could not bear the itching and as she mentioned “*I used to leave whatever I was doing, I would sit, start scratching it. I could not focus on my work, sleep, leisure (usually watch Television)*”

(Veerapuram, 1, December, 2016). Then she noticed the spreading of the condition all over the body. Later she visited around four doctors to treat her skin problem. Initially she visited an allopathic practitioner and the doctor said that the condition must be due to some allergy and gave her some tablets and ointment. She felt little better till she was consuming medicines and applying the ointment, but then itching started again all over the body. She then visited a Siddha practitioner as advised by her neighbour. She got some oil to apply from that practitioner but it took a longer time to heal. Hence, she decided to visit another doctor in the town, but the story repeated itself. Finally, her sister made her visit a hospital at Tambaram (part of the capital city, Chennai located closer to the head quarters), where the specialist treated her and asked her to go for a blood sugar test. She was diagnosed with diabetes and the doctor prescribed medicines for sugar also. Then she felt better and continued treatment for sugar in a hospital closer to her place and cheaper than the above said hospital.

Similarly, Mrs. S, 40 years, from scheduled caste group also experienced itching and took medicines two times when she was feeling better. She got the relapse of itching within a few days. Meanwhile her neighbour who attended an awareness programme on diabetes informed her that itching or a wound that does not heal is a symptom for sugar (diabetes) and asked her to visit the nearby clinic (run by Rural Women's Education Centre (RUWSEC), an NGO). She visited the clinic the next day only and she was tested for sugar and diagnosed with diabetes.

Mr. E said that he had frequent urination which he could not control. So, he started reducing his water consumption, but he was feeling thirsty. If he would not drink water, his throat would become very dry. He could manage this during the day but he was disturbed during the night. He used to continue sleeping late in the morning, which affected his routine and went to his work late few a times. He used to do agricultural labour in a team on contract and they also would go to other villages and sometimes other district too. In order to overcome the continued disruption due to the persistence of symptoms, he visited the health facility within few days of experiencing the symptoms and was diagnosed with diabetes.

But Mr. P (46 years, from scheduled caste) was an ambulance driver at a clinic. He tried to visit the doctor within few days of experiencing giddiness. Similarly, Mr. D (45 years, from scheduled caste), who worked as a hospital servant had immediately reported to the doctor when he was feeling giddiness. He got checked for blood sugar which was found to be

abnormal, and he received the confirmed the diagnosis of diabetes the next day with the fasting blood sugar.

4.4. Social Comparison, Lay referrals and Validation of Symptoms and Diagnosis

From the experience of Mrs. M, it can be interpreted that persistent symptom occurrence i.e. severity of the symptoms made her worry, as it was intolerable. It is this that made her seek treatment. When the symptom was mild she had applied coconut oil, based on previous knowledge and after consulting others in the community (the process of social comparison). But when the symptoms were getting severe, she started visiting the health facilities located closer to her village. She also needed someone to accompany her to the hospital at the headquarters. Upon further enquiry, it was observed that her husband was involved in farming continuously during those days and she had to support him in the field and also prepare food for the labourers and take care of cows. This delayed her treatment seeking to the specialty centre, which was located at the district headquarters. When the work got over, her husband agreed to take care of cows and then she went with her sister to the specialty centre.

From the above example, when the symptom was persistent or worsened even after applying coconut oil, she had reached at least a nearby hospital to get relief from the symptoms. Hence the individual had tried to prioritise the symptom experiences (skin itching) and took action. When other roles and responsibilities were equally important and when she was also in need of someone accompanying her to the hospital, the action taken was delayed further. Hence the family roles and responsibilities and dependency status (here referring to need one's company to travel to the headquarters) influence how people act on the symptoms and when they can take action.

In the case of Mr. E, he was referred to the hospital by his friends who used to go with him for the contractual agricultural labour work. When they suspected that his symptoms might be due to sugar, they took him for the test.

The symptom experiences and treatment seeking behaviour of Mrs. V and Mrs. A are different from Mrs. M and Mrs. S. It was a shock for Mrs. V when she first noticed boils on toes when she woke up in the morning. She thought that someone did black magic. She took a bath and prayed to the deity to alleviate the boils and punish whoever cast a spell on her. After she returned home, her husband noticed this and said that this must be a kind of leprosy

(perunoi) and asked her to die. He said that he was unwilling to spend money to cure her disease. She felt very sad and lied down on the floor for two days. Her father visited her the next day and asked her to come to the hospital with him. But she shared with him how deeply upset she was with her husband's behaviour and was not interested in visiting the hospital. She just tied a cloth around the boils. Then next day, the lady who used to sell curd in her village saw her feet and informed her to visit the doctor. She also said that the occurrence of boils might be due to 'sugar'. She mentioned that she had seen someone with this kind of boils who had 'sugar' disease. At this point, Mrs. V felt that this lady was her saviour. As she expressed,

“ She, the curd seller was my saviour then, God only sent her, if she would not have told about this I would not have visited the doctor, I would have done some home remedies and left those boils as such”. (Mrs. V, Karumarapakkam, 25.11.2016)

Later Mrs. V visited a private clinic in the neighbour town Tirukalukundram and complained about her condition and also her conversation with the curd seller. The doctor advised her to go for a blood test and found her blood sugar was high (around 400 mg/dl which is above the normal limit). She was informed that she has diabetes and was given some tablets for the boils and diabetes. She was also given a liquid to apply on the boils. She was advised to take the 'sugar' tablets regularly. She was asked to visit the doctor after two days to check for fasting and post prandial (after food) blood glucose test. The wound was healing and her sugar level was found to be lesser than the first day. But the doctor advised her to take her medicines regularly. Her husband was fine after that and felt sorry for telling her that she had leprosy.

Mrs. KB, a 54-year-old Muslim woman had asthmatic condition. She was continuously having it. She could not consume food regularly and felt giddy. But she ignored this and took rest whenever she experienced it. She associated the giddiness with her irregular food habits. She used to visit 'Dargah' often and also stayed there for some days. When she was at the 'Dargah' she would never experience the symptoms, which she used to experience at home. So, she interpreted that her symptoms were due to some black magic done by her relatives. One of her daughters committed suicide recently. She said that her daughter died due to black magic (sooniyam), which was the act of a relative who was staying in their home then. So, she used to go to 'Dargah', which was located very far from her village. When she was feeling sick another daughter was there to take care of her. When her daughter was not available, she could not perform household activities on her own. Hence after experiencing tiredness and

giddiness for several days and unable to perform her activities with no one to help her in the household chores, she decided to go to the hospital. She discussed the matter with her husband and asked him to take her to the Government Medical College and Hospital at Chengalpet for treatment. Then he took her there for treatment and where she was advised to go for blood sugar and diagnosed with diabetes. (Information collected from Mrs. K on 01.04.2016)

Similarly, Mr. K, 48 years, a marginal farmer, experienced fever for three to four days. On the second day of fever, he got tablets from the pharmacy. For a few hours he was feeling better but later he started having fever again. Then he visited the doctor who advised a test for dengue and gave him medicines. The test for dengue was negative but the doctor suggested more blood test for other fevers. The relatives of his wife asked him to go to the temple to get a sacred thread to be tied around his wrist to heal the illness. His wife took him to the temple and even after tying the thread he said

“Only one or two days I was feeling better, but later I realized that it was a kind of faith that made him feel better. Finally, I went to the specialty hospital where they advised to go for blood sugar test and then I came to know I am having diabetes and the blood sugar level then was 380mg/dl and the doctor spelled it was high and prescribed medicines”

“I also had urinary infection which I could not reveal to the doctor as people were there around me whenever I visited the doctor’s clinic. After I started taking the tablets, everything became normal”. (Mr. K, Ammanampakkam, 13.02.2016)

Drawing from the experiences of the study participants like Mrs. V and Mrs. KB and the researcher’s observation in the field, it is clear that people attach sudden and acute illness like fever, stomach pain, diarrhoea and so on, with ‘evil eyes’ or ‘black magic’. This belief was highly prevalent in the study villages especially when children experienced illness. Then they would pray to their family God (kuladeivam) or deities at home or temple and apply holy ash on the forehead (holy water too sometimes) or tie the yellow thread around the wrists of the affected ones.

4.5. Process of confirming and re-confirming the high blood sugar (diabetes)

Mr. PA, 50 years old, running a tea shop (in which he used to prepare snacks and food items) mentioned that once he was a little aggressive with a customer. Another woman customer who was present at that time in the shop advised him to go for a check-up for high blood

pressure and blood sugar test. She worked as an attendant in a clinic and recognised the early symptoms of diabetes.

“I was making a joke to that lady “do you want to add a patient to the clinic?”. But after few days I was feeling giddiness during morning time, sometimes feeling hungry too. I would take tea and I would be alright. Usually I would wake up around 4.30 a.m. to prepare tea and I would slowly do the preparatory work to prepare ‘tiffin’ items in the morning. My wife used to go to market in the morning and when she would come back, I used to come home for some time and refresh and have breakfast and then go back to the shop, continue my work” (Mr.P, Karumarapakkam, 17.02.2016).

He added further that *“One day I was having the similar giddiness and I took tea with little more sugar also as I thought sugar would help me become normal and I went home. Even after I freshened up I was not feeling alright. I went and lay down for some time. Then I tried to wake up, but I could not, my head was heavy, my vision become double and then I asked my daughter in law to call my wife at the shop and once she came home we went to the hospital. The doctor asked me to do a blood test and I was informed that my blood sugar is high and asked to confirm it with a fasting blood sugar the next day. Yes, the next it was confirmed that I became sugar patient, started taking tablet, started going for a walk and all in the initial period, but nowadays I could not go for walking (because of winter also). Morning time and evening hours are the peak tea time, when I preferred to be there in the shop as my wife could not handle single handed” (Mr. P, Karumarapakkam, 17.02.2016).*

He also went to another hospital to confirm the status of diabetes.

Similarly, Mrs. A was explaining that how she was repeatedly going to different health points to confirm her status of being a diabetic.

“Whenever I get fever and all I used to visit Dr. AR’s clinic at Tirukalukudram for treatment. They would not do anything on first day itself, they would give some tablets only asked to come on the next day if fever continues. Later on second or third day they would ask to go for blood tests and with those reports they would change the treatment with some other tablets and injection or a glucose bottle. Similarly that time also I was not relieved of my fever and hence I visited on third day when they asked me to go for a blood test and then they told me that I am having sugar and need to take this treatment regularly” (Mrs. A, karumarapakkam, 25.03.2016).

“Two months earlier, I went to Tirukalukundram Government Hospital with my husband and where they tested me also for blood sugar and said there is no high sugar and it is normal only” she added.

As her sugar level was normal two months ago, she wanted to confirm this diagnosis in another health facility. She went to another health facility where her relative used to work in the lab. Her blood sugar was found to be high even in the second facility. Her relative suggested a higher end diagnostic test, the name of which she could not recollect but remembered paying around 500 rupees²⁴. The report was showing more than 7 and hence they told her that she is having diabetes. She also mentioned that her relative was asking her about the chit business she was involved in and advised her not to take too much of tension and it might increase the blood sugar.

Mrs. S had shared a different story of diagnosis. Mrs. S, 43 years old from a most backward community experienced fever, tiredness, and visited the doctor at her mother’s place where she used to take treatment whenever she fell sick. The doctor treated her for fever. She visited the doctor again as her fever was continuing. The doctor asked the nurse to do a blood sugar test using the glucometer. The blood sugar was around 300mg/dl. The doctor informed her that this tiredness and fever might be due to high ‘sugar’ condition and that she must take ‘sugar’ tablets. She left the hospital and was continuing the fever tablets. Then the same evening, she had a discussion about the doctor’s advice with her neighbour and she suggested her to go for fasting blood sugar test. Later she decided to go to the block PHC to have a fasting glucose as the lab person was available at nearby PHC the next day. She visited there the next morning and confirmed her condition of sugar with venous blood sugar test.

It is observed that the individuals took efforts to confirm that they are suffering from the condition “diabetes” and it shows a kind of uncertainty and fear that they might need to suffer from this forever. The role of social groups such as relatives or neighbours in referring to the better health sources is also noticed. The case of Mrs. S has shown that the individuals are aware of the advancement in the *method* of diagnosing blood sugar better (here venous blood sample for fasting blood sugar).

²⁴This test might be of HbA1c as it matches with the test as she mentioned about the accumulation of blood sugar.

4.6. Dependents and diagnosis of sugar

Mrs. R, 60 years, landless labourer from scheduled caste who is living with her son, daughter in law and grandchildren had complained to her son a few times of giddiness and shivering when she was hungry. He ignored her symptoms and advised her to eat and rest properly. This was happening for several months. Then one day she suddenly fell down and remained unconscious. Then she was taken to the hospital. Earlier she also thought that she should not disturb her son as he had to take care of several other family members. As she said

“Poor guy., he also has to take care of several things in the family, one day I am going to go to graveyard, why to trouble them” (Mrs. E, Perumbedu, 29.02.2016)

A similar experience was shared by Mr. N, aged 62 years. He has two sons. He lived with one son while his wife lived with another son. This was the arrangement suggested by their sons and not either by him or his wife. Earlier, they were living together and cooked in a separate house. After he started living with his son’s family, he was not served food on time and was not satisfied living there. He shared that he was having frequent urination and other symptoms like polydipsia and polyphagia. But he was feeling reluctant to ask for food when he felt hungry. He worked in the agricultural field and also went for NREGA. The symptoms started affecting his activity and he needed to rest often. Once he was lying down half-consciously, and his wife who came to visit him made her son take him to the hospital where he was diagnosed with diabetes.

But Mr. T, who is a retired teacher from a backward caste group, had experienced his diagnosis differently. He used to get invitation from the villages whenever some events like sports competition was happening. Once he was asked to conduct football competition for the children in a village as part of a festival celebration. He went there and conducted the competition. There were other programmes also going on and it was hot so he sat in the shade and was watching other events. Then somebody called him for something from a far-off place on the playground. He tried to respond by getting up from the place. When he got up, he fell down due to giddiness. People next to him tried to hold him and gave him water. He was immediately rushed to the hospital where he got to know that his sugar level was high. The doctor advised him to have a fasting sugar test the next day and then confirmed that he was diabetic. He was asked to continue with the oral hypoglycaemic agents.

4.7. Time taken by the participants to visit health Facility

When we look into the kind of the symptoms experienced, it differs from individual to individual. It also depends on the duration and severity of symptoms. As the distribution was not normal, in case of the number of days taken to seek treatment or visit a health facility from the onset of symptoms, we considered non-parametric tests for the analysis. The results didn't show the significant variation among gender, caste and class. The percentile was considered too see the difference between the groups. The quartiles were considered to see gender, caste and class variation in time taken to visit a health facility. The 75th percentile is 20 days. It is observed that proportion of the participants took more than 20 days was about 20%. The proportions were little high among females (22.2%, N=117) than males (17.1%, N=76). Similarly the proportion of BCM (33.3%, N = 15) and SC (26.3%, N=80) who took more than 20 days were comparatively higher than other caste groups such as MBC(11.1%, N=63), BC (17.9%, N=36) and OC (14.3%, N =7). Likewise, the class wise information showed that proportion of landless labourers (28.3%, N=103) was more while compared to other classes like marginal farmers (5.9%, N = 34), small and middle peasants (14.3%, N = 14) and people /family members who hold government positions or retired or hold professionals like engineers (14.3%, N=42)

But the variation is shown in terms of where they initiated treatment and where and how they continued the treatment. Before capturing the process of treatment it is important to situate people's understanding on diabetes and treatment. It is also equally important to study the health care provider's understanding of diabetes and treatment. Further this will throw insights on the interaction of the patient –health care provider in accessing and providing health care for diabetes in a given health care setting.

4.8. Patient's perspectives on diabetes

“For in the context of chronic disorder, the Illness becomes embodied in a particular life trajectory, envired in a concrete life world” (Kleinman A, 1988, pp.31). Narratives about their disease onset brought out several linked events or incidents that happened in people's life. Narratives may be viewed as shared interaction of the individual with his or her social context and not only an isolated unit of a discourse (Loewe et al., 1998). Their manifold discourse on falling ill and illness itself would give us the broader meaningful understanding of the circumstances and context in which one would experience what kind of struggle, how one would tackle that, what kind of suffering it produces in physical, physiological,

psychological state of the individual. The narratives also bring out the macro social forces that have a link with individual's life and health which are more economic and political in nature.

Mendenhall E (2010; 2013; 2017), using the illness narratives of the Mexican immigrants, had explicitly shown how diabetes was used as 'idioms of distresses'. They expressed the acute or prolonged emotional stress and sufferings, which were more of social and structural in nature and how those sufferings remained as a reason for the production and co-production of depression and diabetes. The study further showed the micro and macro social factors which affected individuals in several spheres of their lives that were layered and interwoven with each other. She applied the syndemic framework²⁵ in studying the poor immigrant population affected with diabetes. She coined the term VIDDA (Violence, Isolation, Diabetes, Depression, Abuse) syndemic and illustrated five main dimensions of health and well-being.

She took narratives of women and explained these five dimensions and had how it interacted with social and structural spheres of their lives. For example, she situated Domenga's lived experience of long-lasting abuse since her childhood by her own father and how eventually she went through several other life stressors such as living without citizenship in Chicago for years, then her marriage, later her husband's death, raising two children by protecting them from the neighbourhood violence and showed her resilience by trying to continue live her life with diabetes. Mendenhall (2013) situated this in the larger political context and illustrated that the loss of social protection which could not save her from sexual abuse, economic instability of the family as a result of structural violence. The author also figured in symbolic violence and she puts it as "symbolic violence figures in Domenga's fear and shame to talk to others about her father's transgression: and shame also possibly contributed in some way to her father's violent towards his daughter" (p.47).

Similarly, in the present study about 50% of the women have related their onset of diabetes to everyday tensions in life, worries about things in life, spousal abuse (physical or verbal), poor financial condition, alcoholic husband, unhappy (married) life ('manavethanai' 'mana kavalai'), accumulation of prolonging stress and strain, and inability to control them. While, men participants have linked their onset of diabetes to tensions or worries related to financial constraint, employment, reduced physical activity, changes in work pattern, migration and

²⁵Syndemic is the combination of the terms 'synergy' and 'epidemic'. "Syndemic is a set of closely intertwined and mutual enhancing health problems that significantly affect the overall health status of a population within the context of a perpetuating configuration of noxious social conditions"(Singer M, 1996). It is not merely the addition of two diseases. Beyond this, it would bring out their 'multiplicative' interactions with each other and with other adverse social conditions (Mendenhall, 2012).

consumption of outside food. Some women brought out their suppressed emotions, expectations, other unsettled grief or sufferings in life. Some men linked the cause of diabetes with accumulation of everyday tensions in finding a livelihood source, better wages.

The present study has brought out eight broader domains in how people perceive their onset of diabetes. They are as 1) Everyday stress/tensions in life, 2) Interpersonal violence, 3) Loss of near and dear ones, 4) Heredity and Family History 5) Food transition and physical activity, 6) Nature of Job and disruption in biological routine, 7) Insecurity and constant anxiety and fear about life, 8) Diabetes and Reproductive Health

4.8.1. Everyday stress/ tensions in life

“We took loan from a money lender for our daughters’ college admission. We were about to harvest the paddy in the field. We were planning to repay that loan once we would finish harvesting and selling the paddy. But before then only the time to repay got over. The money lender came to our house and started shouting. My husband was also not there. I was scared and I could not utter a single word then, that moment was so tensed and I was sweating a lot. Since then, whenever somebody would speak loud I used to experience kind of shivering inside me. This was kind of starting point for my sugar I feel. Then after harvesting I told my husband about my kind of fear inside I used to feel and accompanied symptoms like feeling of weakness and sweating. Later he took me to the hospital, where they found out that I have diabetes” (Mrs. U, periyakattupakkam, 06.04.2016)”

Similarly, Mrs. A considered her every day tension of chit business as the entire reason for onset of diabetes. Mrs. A ran a chit business and collected money every week from the people in her group. Few of them took loan and did not repay properly on time. Initially she would visit and talk to them politely to collect that money. But she lost her patience after visiting them few times as there were many people’s money involved in it and she started shouting at them with anger. Then she started visiting them every two days and tried to collect that money gradually. One day when she was talking to one of the persons, she was feeling dizzy and sat in the street and called her son to pick immediately from there. She left for the hospital and got to know her sugar was high. She was associating this tension, which resulted out of her work, with her falling sick (high sugar).

Likewise, Mrs. MB was pointing to an incident of huge financial loss and strained relationship with her brother in-laws as the starting points of her sugar.

In contrast to all the above, Mrs. R has given a broader link of how her everyday tension about livelihood source, life of children and physical stress due to work lead to onset of diabetes

“What to tell, my husband died, I have to take care of 3 girl children. My elder daughter got married two years ago. Other two are working in an export company after they completed their school. We have to save for their weddings know, mean while elder daughter comes very often with one or the other problem. My son in law is not good. He doesn’t go for the job regularly. I also have to take care of her. Her parent in- laws are not supporting her. I will sweep the office and keep drinking water in a nearby company and then attend the work under NREGA. If there is no work under NREGA, I would go to any other work like weeding and other agricultural work. I am getting Rs. 1000 from that company and I will get around 2000 from NREGA work. Usually I try to manage with that for family expenses. I have started rearing a cow since few months. I hope that the family needs can be satisfied fully once cow starts giving milk. I have to repay the loan which I took for my elder daughter’s wedding. I am trying to save little from the younger daughters earning. If they go for their work regularly, then they would get 4000 rupees each, but one after the other they will also experience some illness then health expenses. Some days I feel that whether someone would take up my role, I am becoming weak physically, running for one after the other, the amount of work which I do every day exhausts me! How much I can handle? I think all these tension ended with diabetes” said a 50 years old dalit woman (Mrs. R, Aandimadam, 11.09.2015)

4.8.2. Interpersonal Abuse

Mendenhall E had grouped several experiences which she identified as sub themes, which included physical abuse, sexual abuse or verbal abuse under a broader theme called ‘Interpersonal Abuse’. She described Interpersonal Abuse as “any behaviour designated to control, and /or subjugate another human being through the use of any mention of emotional, verbal, physical or sexual abuse” (2013,p.118)

Similarly, those kinds of experiences were grouped under Interpersonal abuse.

“He verbally abuses me every day, find faults in cooking, taste, like everything. He always creates problem for me. He gives lots of tension every day, because of him only I got diabetes I think. I am not at all happy with this man. He never had given happiness to my children too. We do not have peace in the family. “mana nimmathiilla” (do not have peace in

the heart) you know my daughter used to work in an export company, that too in shifts. She used to go early morning and come by 4pm in the evening. Some days she would eat lunch, some days she would skip it. She used to sleep as soon as she would come back from work. Within an hour or two, my husband would come home started shouting at me for no reasons, he would start fighting with my children too. It is disheartening that he would sit in the portico, and orally abuse me /my relatives in drunken mood. This would defame me a lot in my surroundings” (Mrs. R.Perumbedu, 23.03.2016).

She added “My daughter stopped schooling after 10th and started earning. This man never gives money for family expenses. He usually spends money only to buy beef or fish and some days he used to buy vegetables. He would force me to cook then. He used to fulfil his stomach. He never used to think about others. He would never ask me that whether I and my children had food. My daughter is putting on weight day by day. I am scared that whether she would get diabetes very early” (Mrs. R.Perumbedu, 23.03.2016).

“I suffered a lot because of this man, his sister in law and others in his family. He used to beat me, kick me every day those days. He is good to everyone. He used to call me without reason and would beat me if anyone would come and question him. He would never respond them. Once my brother in law came and tried to stop him from beating me, he didn’t tell anything to him. But later he used very abusive language and blamed me that I had developed a dirty relationship with my brother in law. Since then I used to tell everyone that this is between us ‘husband and wife’ please don’t interfere in our problem. But without tolerating this my mother in law’s sister, she informed my brother about this torture I am going through, then my brother came here and spoke with him. After that he kept quiet for some days but started again. It is all because of my aunt(my paternal uncle’s wife). How much tears, How much sad I was, still existing, I hate him and I don’t like to go closer to him, I did not want my children to be born, but it happened, He never spoke to me with concern, he never fulfils even my small.. small wishes still having wishes..not fulfilled. “intha mana kavalai..mana vethanaiyumthaanavaloseekiram diabetes varakaranam”(this sadness, this pain in my heart is the only reason to get diabetes that early). U know, my uterus was removed at very younger age.I didn’t know that uterus was prolapsed before. I felt some lump was there, I could not sit properly. It was painful too. Then I shared this with a woman who used to work in our agricultural field that something is there, that too after 3 years. Later only she informed my husband and he took me to the hospital. Then the doctor advised me to remove the uterus”(Mrs. K, Pattaraikazhani, 13.10.2015& 29.12.2016)

She got diabetes when she was 30 years old and now she is 68 years old. Recently she has undergone cardiac surgery. She was also suffering with foot ulcers for several months earlier to this surgery.

4.8.3. Loss of near and dear ones

Mrs. M, 40 years old widow mentioned that she got diabetes because she could not bear the loss of her husband two years back.

“He was sick only when he died. But if he would have been alive, I would have that feeling of strong support in life, a great strength to handle things better. But now, I also become sick. When his death happened, my daughter stayed with me for few days and went to her in-laws place. I was alone at home then. I could not sleep properly, I used to think about him, I did not cook and I did not eat properly. All these together stressed on my body and I got diabetes within 6 months of his death” (Mullikulathur, 27.11.2015).

Similarly Mr. J expressed that his sadness due to loss of his son is the only reason to suffer from diabetes.

“Till today I could not believe that my son is not alive. I could not save him from jaundice and I feel guilty for that. Its’ been years now, I could not overcome it, he took off my happiness. I cannot live a happy life any more. Whenever I would spend time with my daughter, I would recall those moments with him. I could not laugh from my heart as I did earlier. That is the reason I got diabetes also” (Mr. J, Suradimangalam, 25.02.2016).

4.8.4. Heredity and family history

Few others mentioned heredity or family history as responsible for the onset of diabetes.

One of the participants said that *“Everyone says diabetes is hereditary. They also said that your grandmother had earlier and you are having now. It is because of you, now your daughter also got diabetes” (Mrs. U, Periyakattupakkam, 06.04.2016)*

“My mother had diabetes, then two of my brothers got it, then I got it, one of my brothers died due to kidney disease. This is due to diabetes only. I heard from doctors that diabetes is hereditary and it can pass from generation to generation. That is how I also got it” (Mrs. K, Kunnavakkam, 04.04.2016).

“I never used to have more sweets, but how did I get diabetes? My parents did not have diabetes. My paternal Uncle and Cousins have diabetes. It must have been there in my generation long back might be my grandfather or grandmother. I think I too got diabetes from my family” (Mr. A, Mullikulathur, 024.04.2016).

4.8.5. Food transition and physical inactivity

Few others associated the onset of disease with the transition in food habit, crop cultivation, and mechanization (hence decreased physical activity). As expressed by a 39 years old female participant from Pakkam:

“We get diabetes due to our food only. I think it is all because of pesticides which we use for farming. Earlier they use the natural fertilizers (iyarkaiuram), all tree leaves (thala / elai) as fertilizers. That’s why earlier days people were healthy and nowadays people are getting disease like diabetes” (Mrs. A, 07.03.2017).

An elderly person described how people are getting diabetes in their younger age nowadays by comparing his food habit and physical activity with his son’s food habit and physical activity. He then differentiated the period of onset of diabetes of people in his age and people in his son’s age.

“Earlier when I was young, my father made me to work in the agricultural field and got to school. But now days the children either involved in studies or watching TV, not even go out and play. I remember well that when I was doing my teacher training, I used to eat ragi ball / koolu during morning, afternoon only curd rice. Some days, rice with water and pickle only or I would get ‘naalana’ (25 paisae) to buy vada for side dish.. Sometimes my mother used to give raagi koolu for lunch too. Whenever we used to cultivate vegetables, she used to prepare vegetables. But we use pulses, green leaves and all often. During some festival days, we used to have non -vegetarian food. But now days, people are eating fried rice/ biriyani every week. Un limited snacks and cool drinks are given to children, you see I got diabetes during late 60s but my son got it in his late 30s. I think because of reduced physical activity only, people get diabetes at younger age. My son also, he never used to involve in the agricultural activity. He used to study always and started going for job, became more sedentary but when after he was diagnosed with diabetes, he started his morning walks” (Mr. S, Suradimangalam, 13.10.2016)

Changes in the food habit, importantly consuming oily /fried items and sweets are commonly attributed to the onset

“During those days (before her 20s) we used to take raagi koolu (porridge of ragi millet) and pulichaikeerai(green leaves) in her house where 25 people (including paternal uncles, aunts and cousins) living together as a joint family. We used to take rice one time a day. I also started eating rice all the times after few years of marriage. Then my husband’s family started cultivating paddy only. Then frequent consumption of non-vegetarian (weekly thrice) also added. During or childhood and all, we used to have non vegetarian food occasionally” (Mrs. M, Mettu Egai, 02.03.2016).

“When we were young we used to consume rice one time only. We would not get snacks like bajji, bonda, samosa in those days. My grand ma used to give us ragi roti (prepared with onion and drumstick leaves)..but nowadays almost all the days my husband used to bring either samosa or pakoda in the evenings for tea. I am also used to it now. Sometimes I used to call him and ask him to bring samosa/bonda when he returns from work” said a forty-five years old woman from Ammanampakkam village (Mrs. K, 13.02.2016).

4.8.6. Nature of job and disruption in biological routine

Some participants mentioned that nature of work and interrupted biological routines are the important reasons for the onset of diabetes. They narrated how the changing work pattern, irregular routines, the timing of food and sleep might have contributed to the onset of diabetes.

“My food and sleep timings are irregular, that is the important reason for the onset of diabetes and also that is the only reason why I could not control my sugar“ (Mr. V, Kunnavakkam, 20.12.2015)

He worked in a canteen, where he had his breakfast around 11am and lunch around 3 pm. His work would complete by 9pm in the night. He would come back home and then have dinner around 11 pm. He would fall asleep immediately after dinner. He used to wake up around 4.30 am, so that he could reach his work place at 7 am in the morning. He would sleep for an hour before or after lunch. He pointed out that this routine might be the reason for his diabetes onset.

Mr. K, 48 years old man explained that how his job made time become diabetic and how he managed to become physically active after getting out of that job.

“I was doing security job for 5 years, all the time sitting, / all the three times meals that is the only reason for putting on weight and onset of diabetes. Now I left the job and engaged in agricultural labour and NREGA/ rearing cows”(Mr. K, Jamberi, 08.12.2015)

Another woman told about her husband who is having diabetes

“Presently he works a lot, walking more, started doing agriculture, lost weight remarkably whereas earlier he used to live in Chennai never involved in any physical activity as he worked in shifts at a Petrol Bunk. Now we shifted here to our village purposely, started cultivating paddy as we have water in the well and will have water in the lake also for some time. Now also he works there in the same petrol bunk but in day shift only, resting properly. When he got sugar, he used to mention that it was because of his work and improper sleep only he got diabetes”(Mrs. S, Pattaraikazhani, 18.12.2015).

4.8.7. Insecurity and constant anxiety and fear about life

Constant fear about onset of diabetes to their younger ones and feeling of insecurity about life is prevalent among the people with diabetes.

“My father died of kidney problem, People are telling me that diabetes will also cause kidney problem, I am afraid that I might get this kidney problem anytime. My life itself is full of problems and diabetes is now added onto it. Earlier I was very happy as my father was alive. My right leg was little bent since my birth. I used to walk very slowly by holding my leg with hand....my father was the one who took serious effort in treating that leg and I got my leg surgery done in Kilpauk hospital you know. As he was more into politics that time, he managed to get a recommendation letter and took me there. I could walk now without holding my leg with hand and I experience severe pain in my leg nowadays”(Mrs. R. Nerumbur, 06.06.2016).

She continued further about how she was going through lot of problems in her married life.

“I am 37 years old now. My daughter is 3 years old. I have many other family problems. He is my second husband. My first husband was mentally abnormal. Without informing me and my family members about his mental condition, they (in-laws family) got

me married. It took 6 years to come out of that life and after that I got married to this person but who is also already married and having a son. Initially they said there is no connection between him and his first wife, but later I came to know that he used to go there and see his son. She (the first wife) is his sister's daughter. Emotional affinity will be there at least for his sister's sake. what to do? my life is like this" (Mrs. R. Nerumbur, 06.06.2016).

She tried several times IUI to have this baby as everyone in the family advised that she would have a hold for her future if she would bear the child, otherwise no use of this life and husband might not stick to her.

Mrs. N was sharing similar experience, which is explained in the next section (diabetes and reproductive health).

4.8.8. Diabetes and Reproductive Health

This study throws light on how diabetes affects Reproductive and Sexual Health of the individuals suffering from diabetes. It is observed that the proportion of the female participants (19.6%) whose age at onset is aged below 35 years is comparatively more than the male participants (9%). About 3.4% of the female participants had experienced gestational diabetes and were continuing with treatment after the delivery. Their shared experiences of how diabetes affects Reproductive and Sexual Health are summarized. One important sharing was on fertility issues and spontaneous abortions of the individuals with diabetes.

Mrs. K, (35 years) had several abortions for more than 5 years. She had to undergo hysterectomy when she was 30. She finally adopted a baby. After 2 years of hysterectomy she was diagnosed with diabetes. When she expressed her perception on cause of diabetes, she first associated the onset of diabetes with rice consumption and her everyday habit of non-vegetarian food item like mutton and fish and consumption of sweets. But later she tried to link diabetes as the important reason for her abortions.

It is important to note here that about 8% of the female participants had undergone hysterectomy, and diabetes onset occurred either few years prior or later to hysterectomy. Few participants also reported heavy menstrual bleeding after the onset of diabetes and they also associated it with the presence of diabetes.

Few participants mentioned about the spousal violence at home and also how they experienced uterine prolapse and hysterectomy. Mrs A, 65 years (Backward Caste) said that

she had very bad time in her married life. Her husband would beat and kick her for no reasons. She then underwent hysterectomy and was also diagnosed with diabetes. She associated her diabetes onset with her physical and mental tensions given by her husband.

Another participant Mrs. S, 28 (SC, Adidravidar) had her first pregnancy in 2006 when she was living with her husband in Chennai where he worked as a construction labourer. She had visited the nearby health centre for antenatal care. She was advised to take care of her anaemic condition. By the end of 4th month, the baby got aborted spontaneously. Second baby also got aborted similarly. Later in 2008, for her third pregnancy she had visited the Primary Health Centre at Nerumbur and where they tested her for blood sugar and referred her to Chengalpet Medical College and Hospital. There she was advised to take insulin till her delivery and to continue with the oral hypoglycaemic agents afterwards. She had followed the similar treatment for the next baby too. She was worried about her weight gain and high blood sugar level. She was trying hard to reduce her weight, but she could not succeed. She felt ashamed of her body shape and also felt bad of nasty comments and advice by others to lose weight. She is a landless labourer who works under NREGA or in agricultural work. Her husband works as a daily wage labourer, working both agricultural work as well as other informal works. She takes alone in all the three meals and can afford vegetables sparingly. Sometimes she consumes only rice and 'karakolambu' (which is prepared by boiling tamarind water with tomato and onions with or without other vegetables)

Similarly, Mrs. G, 26 years (SC Adidravidar) had experienced diabetes during pregnancy in 2012. She continued with insulin after delivery as her sugar was not under control. She had to visit CMC hospital to get insulin twice a month. She had to travel for more than 2 hours and spend at least half a day at the hospital to get insulin and sometimes she did not have enough money to travel. In addition, she had to take care of her two children who are aged 2 and 4 and sometimes she would go for NREGA (National Rural Employment Guarantee Act) work. She also mentioned that earlier she was scared that sugar might affect the baby and hence she tried hard to keep visiting CMCH for insulin. Earlier her mother was there to take care of her. But now her husband also went to work in far off places and sometimes he would visit them after a week. She also perceived stigma over using insulin and hence stopped using it and started using an herbal product called 'diaba care' prepared by the local tribal community. She is worried that her children might be affected with diabetes. She also wondered if diabetes might get communicated to her husband from her.

Another participant Mrs. N (BC, Naidu) who is 29 years old and has diabetes for a year shared her experience of trying for a child as follows

“My first husband died in an accident. I have two children one girl and one boy. After 6 years, my in-laws got me married to another man who knew about my family well. We belong to different caste group and my brother as well as my sister will not speak to me at all. My daughter who is 10 years old living with me and my in-laws (parents of first husband) are taking care of my son. My husband takes care of my daughter well but he wanted to have a child of his own and I also agreed to have one more child and went through surgery for reversing tubectomy” (Mrs. N, Suradimangalam, 25.10.2016).

She continued, *“But I got diabetes then and I tried to bring my blood sugar to normal level by following a balanced diet and regular walking – liquid meal for breakfast, then a fruit later and roti with vegetables and salads for lunch and similarly for dinner. I took one sugar tablet (oral hypoglycaemic agent) for few months and later only diet with regular walking then tried to have the baby through IUI as per doctor’s advice. I tried it for one time earlier it didn’t happen and now I am trying IVF again for second time. Everyone in the family supports me and expects my pregnancy this time. I am feeling scared now that if this pregnancy will not happen, everyone will get upset. My husband used to tell me that I should not worry for anything but its’ giving me a guilt feeling” (Mrs. N, Suradimangalam, 25.10.2016).*

She also added that her doctor was telling her about the importance of body weight. When she attended hospital for the first time for a child, her weight was 54 kg. The doctor told her that she was normal then and should conceive soon. But it did not happen. After two or three years, she consulted another doctor. By then her weight was 87 kg, and when her diabetic condition was found she was advised to reduce her weight. She reduced around 17 kgs in 6 months after following doctor’s advice strictly. The doctor encouraged her to lose more weight. She said that she could not express her worries and guilt feeling to anyone in the family and this further worsened her health condition.

Most of the female the participants were reluctant to share about their sexual health experiences when they were visited for the first time. But later few participants opened up and started sharing about their tiredness, abstinence /disinterest in sex and problems with their partners. Few female participants also shared about sexual abuse by their husbands, affecting their physical and mental health.

Male participants talked about erectile dysfunction and infertility issues. One of the participants shared about the problem between him and his wife. His wife started doubting him about an extramarital affair because of his erectile dysfunction and disinterest in sex after he got diabetes. He also shared that he does not want to share his problem to his wife and tried to take treatment from different health care providers within and across systems of medicine.

It was observed that male members tried to share their problems with their peers and further health care providers in dealing with sexual health whereas female members took longer to visit the health care providers in dealing with the symptoms related to sexual health.

4.8.9. Explanatory Model of understanding and treatment of diabetes among patients and health care providers

When we think of explanatory model of illness and disease, one thinks of Arthur Kleinman (1980;1988), who highlighted the difference in understanding of illness among the patient and his /her family, their neighbours, networks, community and health care professionals. When the person with illness visits the health care provider to seek treatment, he /she might explain the symptoms in their own terms which they might have acquired through his previous experience of illness, acquired knowledge through family members or surroundings. When the health care providers tried to understand this patient's reported symptoms and interpret into a specific condition in their own (medical) terms and which he would also try to locate through the knowledge acquired (like patients) probably through the academic professional training of any systems of medicine, then the patient's illness would shift to doctor's term disease.

The treatment can be effective when communication and understanding between the patient and the health care provider take place properly. Only then it is possible to arrive at a consensus on the process of treatment advice, following the advice by the patient, acceptance and satisfaction of the treatment based on the recovery of the condition i.e. alleviation of the symptoms. If there is any miscommunication and misunderstanding between the patient and the health care provider, this might make the provider's (doctor's) interpretation of symptoms wrong which would have a negative effect on further treatment. For instance, a patient may communicate his condition of frequent thirst as dry throat and the doctor might end up treating the dry throat instead of frequent thirst which is an important classical symptom for diabetes (Watkins PJ et al., 1982)). This is similar to a patient having persistent cough who

seeks treatment and gets cough syrup when he is actually suffering from tuberculosis and needs treatment for it (Banerji and Anderson, 1963).

These kinds of interactions prolong the sick days of the patient and also create dissatisfaction with the provider or the health care services. This also might influence the patient to move from one health care provider to another in search of better treatment (Arutselvi D, 2013). Hence, it is important to understand the social and cultural aspect of the patients by which the health care provider would be in a better position to understand their language and symptoms of illness in order to provide appropriate treatment. This would relieve the patients from the suffering of the symptoms and further help them in continuing the treatment.

Hence when we bring out the concept of health or illness we need to bring out the social and cultural aspects of it. Radley A (1994) had put forth that concept of both health and illness themselves are social dimensions. He further argue through Parsonian view that individual who would fall ill need to take up the role of being sick due to the person's inability to carry out his/her normal role. During the period of sickness when the individual is suffering would be relieved from everyday duties is allowed. This relief would be sustained until the individual would seek professional help to recover soon and take up his/her everyday duties.

Radley A also argued through Parsonian view that "doctor as aiding the patient to recover, not just 'biological health', but his or her ability and willingness to resume social life. Therefore, the work of the doctor and of medical practice in general, is a form of re-socialization in that it works as a mechanism of social control. The sick role is an adaptive device within society, ensuring that deviations from social norms are countered by the restoring the ill to the world of health" (1994; pp.11&12). Here the concern is the "functioning of the social order" which is partly maintained by the role of medicine in the society. This might differ from one illness to another and also one person to another as it depends on how they experience, perception of experience, resources available to deal with the suffering.

As health care providers play an important role in getting the patients back to their normal condition and they are also part of the society, it is important to study their perspectives of health and illness in a given context. According to this present research, this explanatory model is importantly envisioned to project the understanding and treatment of diabetes among the patients and also the health care providers. The perspectives of patients and health care

providers about causes, symptoms and diagnosis and treatment of diabetes are explained below consecutively as figure 4.2, figure 4.3 and figure 4.4.

Figure 4.2.: Perspective of patients and providers on Causes of Diabetes

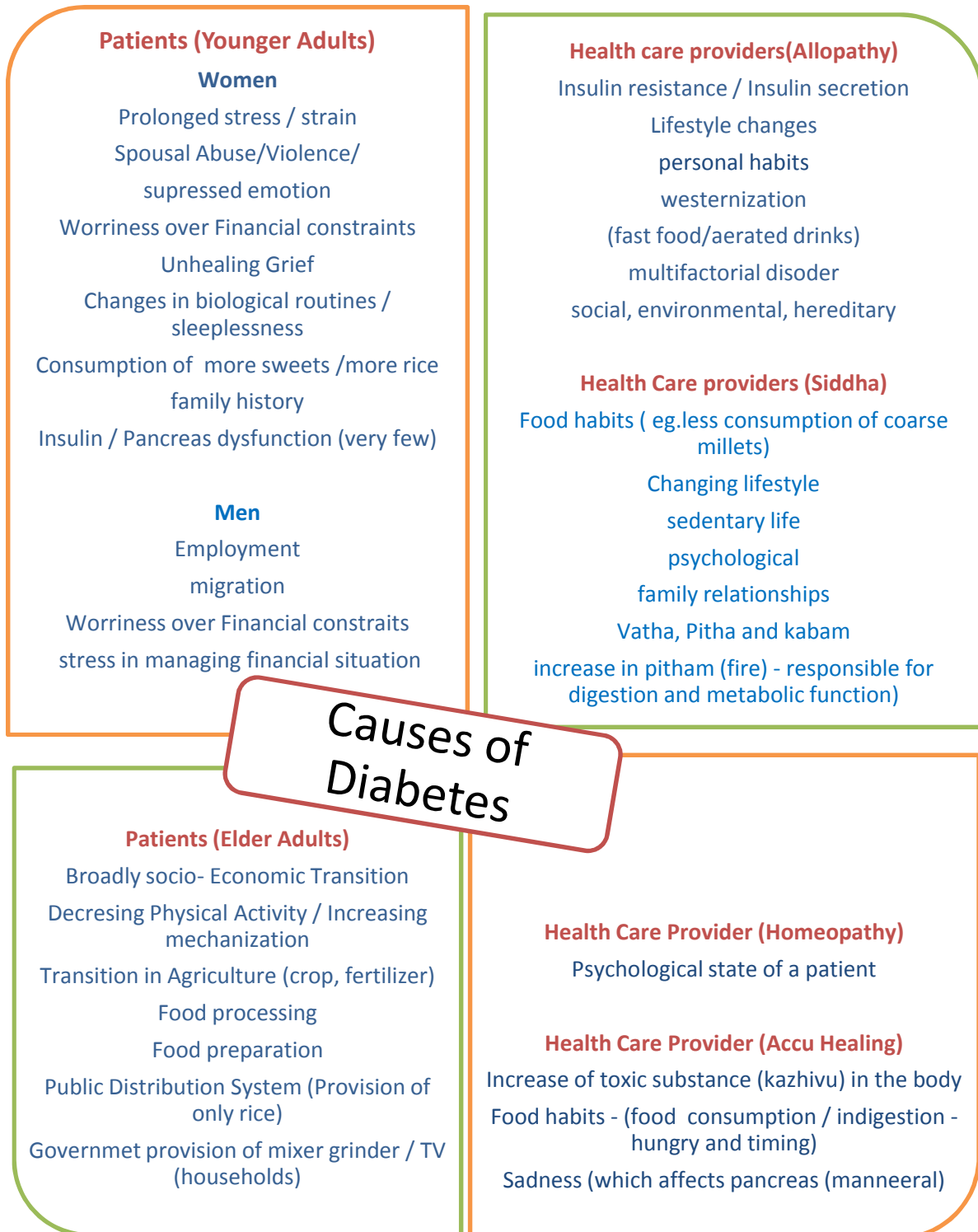


Figure 4.3: Perspective of patients and providers on Symptoms and Diagnosis of Diabetes

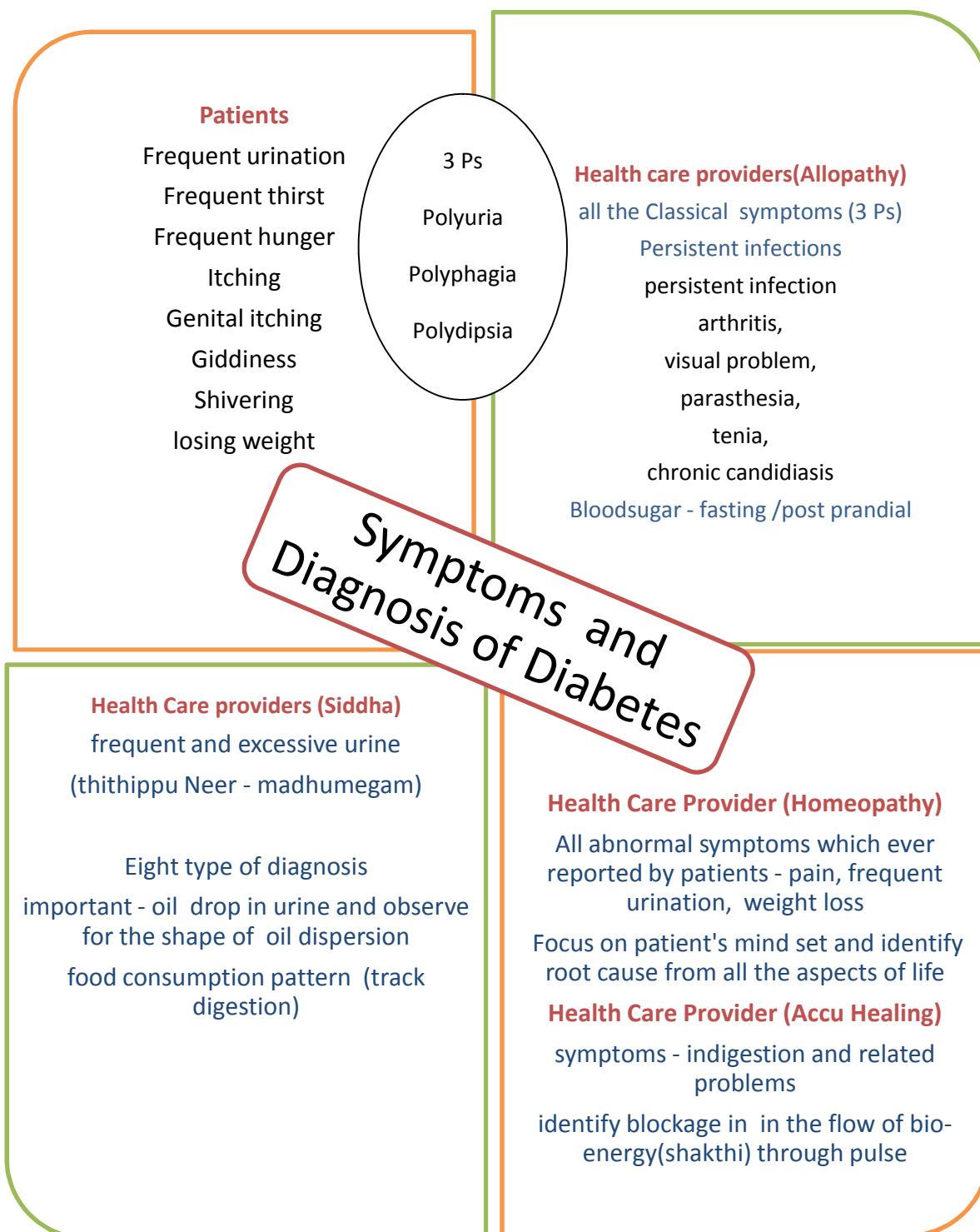


Figure 4.4: Perspectives of patient and provider on Treatment of Diabetes



4.8.9 (a) Explanations on Causes of Diabetes

It is found that the explanatory model on causes of diabetes varied highly between the patients and the Allopathy practitioners. The patients attributed their diabetes onset to chronic tension/stress in life such as financial constraints / employment problem in the family, interpersonal violence such as spousal violence, interruption in biological routines and which are of social in nature. Very few patients pointed out insulin dysfunction or family history as the reasons for onset of diabetes. On the other hand, the Allopaths expressed insulin resistance and genetic factors as the main causes of onset. These factors are of physiological in nature. It is noteworthy that both the patients and the health care providers pointed out 'changing food habits' as one of the reasons for onset of diabetes except homeopathy practitioners.

One of the health care providers mentioned that diabetes is more of social than bio-medical nature. He listed many factors which causes diabetes and divided his understanding in two phases. One is pre-public health understanding, which is more of bio-medical in nature, and the other is post – public health understanding, which is more of social in nature.

It is interesting to note that one of the providers (Allopath practitioner, a post graduate in community medicine and trained in endocrinology) has given a much broader understanding on cause of diabetes as follows

“There are so many things like heredity and dietary factors and lack of physical activity and obesity and family history and so many reasons. And more than all these things I think rapidly changing lifestyles and rapidity with which life is progressing now, rapid change in things from agrarian to industrial society, population explosion, restriction of walking spaces and public spaces, then change in lifestyle in terms of reduced physical efforts, reduced physical activity because of machinery and improvements in technology, changing and westernising dietary patterns, increased use of refined sugar in food, fast food, then things like totally different food patterns which are new like things which were never known to our culture. Food items like pizzas and burgers and fast foods and stuff like that. I think a mixture of all these factors put together could lead to diabetes” (Dr. VP, 25.01.2016)

The patient's understanding on cause of diabetes is very much congruent with the health care providers of other systems of medicine such as Siddha and Accu Healing than Allopathy.

4.8.9(b) Explanations on Symptoms, Diagnosis and Treatment

While we take other aspects such as understanding of symptoms, it is more or less similar between patients and the Allopaths. But the Acupressure/Accu Touch healer and Homeopathy practitioner are deviated from others' understanding of symptoms. This is because their principle in understanding health and well-being is different from others. Homeopathy focuses more on the root cause of the problem, mainly of psychological/emotional in nature. As expressed by the practitioner

“We used to identify the factor which is responsible for the onset of symptoms and treat body as a whole not the parts of the body. For instance, if one is having head ache, we will not treat only the head ache instead we will try to explore the reason from the patient only by studying him or her from all his life aspects such as social, psychological, spiritual, his routine life, life style etc. Then try to build that attitude, a kind of faith that he /she can handle this illness/ situation well and then give medicines accordingly. Sometimes medicine is also not required to treat a patient. I do not want to suppress the body's natural response (as they do in allopathy by giving full doses of chemicals) (Dr. C, 01.10.2015)”

The principle of Acupuncture Touch is also different from other systems. The Accu (touch) Healer would focus on identifying the blockage or stagnation in energy flow in the body. It is said to have certain points for certain conditions. When body gets toxified, then it will interrupt the normal functioning of the body. The blood glucose which is not utilized by the body and remaining in the blood is considered as a toxic substance (in case of diabetes). By stimulating the points, the blockage in the energy flow will be released and detoxification occurs for normal functioning of the body. As the Accu healer mentioned

“It is a natural process; the detoxification can occur through diarrhoea or frequent urination and it will settle down when the body totally detoxified. One should not bother about the level of sugar in case of diabetes. If patient feel more discomfort, they are given accu touch. If, they are at home, they are also taught through phone that which point can be touched or pressed lightly to relieve from the symptoms” (Mr. S, Sembakkam, 09.04.2016).

Similar to homeopathy, patients are not restricted to selected food items. But few items are restricted in few cases depends on the individuals and nature of the condition.

Whereas the Practitioners of Allopathy focus on maintaining normal blood sugar by treating the patients either with lifestyle modification or prescribing mono therapy with oral

hypoglycaemic agents or insulin or combination therapy. Only few practitioners mentioned about stress management. But Siddha and Homeopathy practitioners are giving more importance to the psychological aspects and the family relationships in treating the patients.

As Siddha practitioner said

“Manachikkalum, Malachikalum illanna manusanukku enthanoyum varathu” (in Tamil) means “If there is no trouble in mind and no trouble in stool excretion (constipation), no disease will affect human being” (Dr. S, 01.11.2015).

4.8.9(c)Peer group discussion on following treatment (physical activity)

It is also important to note that the need for physical activity is mentioned by the Allopathy practitioners and very few female patients. However, they mentioned it as an advice which they could not follow. There are men who tried to walk in a group from one village to another. For instance, Mr. S, shared:

“We used to sit in the street and discuss about everyday news. Then one day one of my friends started telling about the doctor’s advice on walking. Then he also shared that as he used to go to the farm early in the morning he could not walk in the morning. Then they had discussed that they would spend time for walking in the evening and we started walking also and continue for minimum 3 to 4 days in a week” (Veerapuram, 20.10.2016).

This group of 4 to 5 men started walking in the village of Veerapuram are belonging to the most backward class mainly ‘Naicker’s caste group’. This group is considered to have a strong network amongst them compared to other caste groups in those villages. This association might have driven a group of participants (8to 10 members) to attend to the same ‘Accu Healer’ for their health issues. Six of them were attending for their ‘sugar’ problem. (The process of how people started taking treatment and their health status and dynamics in following accu therapy is discussed in chapter 5).

Similar kind of group walking was promoted by RUWSEC in few villages. Earlier there were volunteers who were involved with them and walked together. But later they stopped one by one. Few women were walking whenever they were getting time. Later fear of hypoglycaemia made them stop going alone for a walk. This was the expression given by the group of backward class Muslim women.

4.8.9(d) congruence between the earlier studies on Explanatory models and current study

This finding shows similar pattern of explanation for the onset of diabetes as the study done by Cohen et al 1994. The study by Cohen tried to bring out the variation in five topics which include aetiology, time and mode of onset of diabetes, patho-physiology and treatment. In this study, the explanations are again reduced to factors; quantified and analysed the congruence between the patients and the health care providers using statistical analysis did not show any variation. But the variation in terms of explaining the process of how doctors' discussion on monitoring their blood glucose and record maintenance, advice on necessary 'tight control' in maintaining blood glucose levels. This kind of explaining process is found to have much clear picture than the one which was quantitative.

Again, as the authors mentioned that the providers have different orientation (more of disease) in understanding the disease, assessing the severity and further treatment which aims at bringing back 'normal' condition by means of physiological symptoms and biochemical indicators. Whereas the patients have different orientation of understanding (more inclined towards illness) and which has an interaction with the self (subjective experience, knowledge), family, community and more of social in nature. Here being normal lies in the 'feeling' of a patient which is psychological and also physiological in nature to some extent as the symptoms are controlled or alleviated to bring back to normal.

The other study (Loewe R 2000) also brought out similar differences between the patients and health care providers in understanding diabetes. The author reported that the health care provider (medical student/ resident) expressed their concern for onset of complications such as kidney diseases. Whereas the patients "seemed relatively unconcerned about the effect of diabetes on internal organs" (p.385) for the question "What's worrisome about diabetes?" and also out of 22 patients only one mentioned about the pancreas. As this study was conducted in a hospital, this kind of responses could much reflect on how much patients are informed or educated during health education session. This further reflects responsiveness of the health care system, broadly represents the structure and function of the health care services (a training health facility). However, the study emphasised more on studying the clinical implications of the discrepancies between the patients and the provider and attempt to frame 'the elements of a theory of clinical practice centred on the care of diabetes patients' and

specifically ‘a more dialogical model of care’(pp.396) and which might be useful in promoting a more self-reflective physicians.

In contrast to this, our current study has shown a pattern that patients whose family members were already affected with diabetes and died of complications, they are more anxious about onset of complications. Half of the patients who do not have family history also expressed that kidneys and eyes may be affected in future. This also reflects on the awareness campaign/programmes conducted through government and non-governmental organisations.

The previous study in 1998 by Loewe R had argued that doctor’s narratives are equally complex and the stories told by the doctors regarding diabetes are also shaped by the cultural and class differences between the provider and patient. The author brought out the dynamics in narrative construction of how doctor’s narrative would be more of ‘episodic’ in nature and how ‘the patient caught up in the act of daily life. It is interesting to note how the physicians are making intuitive stories to convey to the patients about the internal process of high sugar and onset of serious complications like foot with a stress on everyday check on the feet. On one side doctors wanted their patients to understand the progressive nature of the disease and the other side, it also imparting a sense of fatalism within the patient.

It is observed from the current study that around 20% the participants are either taking home remedies such as fenugreek, bitter gourd, insulin leaves or attending other systems of medicines to treat their condition. It is also found that few of the Allopathy practitioners have encouraged patients to consume bitter gourd juice, which both people and in this case the health care provider feel has an effect on blood sugar control.

Given the extent of the multi-availability of health care resources, people also have multiple options to try out different systems of medicines to care for or cure their condition of diabetes. This, however, can also put them in dilemma about which provider to approach for treating their condition. As this research study focuses on the process of coping, one of the important aspects is studying the interactions between the health care providers and the patient in accessing health care services in the given context. This is discussed in the chapter 5.

CHAPTER 5
Everyday Coping with Diabetes

It is important to locate an individual's living condition while looking into the everyday coping with diabetes, as the two cannot be separated from each other. The individual cannot be seen independently, both from his or her social and living contexts - the family and the community. When we discuss an individual's living condition, it includes his or her roles and responsibilities as a member of the family, work and extended social relationships, and the complex interactions between these different spheres. This has an influence on the behaviour of the individual and shapes his or her everyday activities. Similarly, when an individual is diagnosed with diabetes, he or she has to learn and adapt to living with this condition throughout life, with a focus on keeping the sugar level under control.

Clinically speaking, to keep the blood sugar level within the normal range, one has to follow a balanced diet, regular intake of medicines and routine physical activity, which are referred as 'three pillars' of diabetes management. Everyday management of diabetes includes balanced diet for every meal and a consciousness of quantity, for instance, less carbohydrate, high fibre, and regular intake of medicines, such as one or two Oral Hypoglycaemic Agents (OHAs) and vitamin B complex. If the patient suffers from co-morbidities like hypertension, hyper or hypo-thyroidism, high cholesterol, Tuberculosis or asthma, then medication for these must be included. Following this medication regimen on time, before or after food, becomes part of the patient's daily routine life. Further, people with diabetes are also advised to do regular physical activity like walking or exercising, apart from daily activities such as household chores or physical labour as part of work. People are also advised to quit smoking and consuming alcohol as these impede the maintenance of normal sugar level. The ultimate goal of diabetes management, then, is the maintenance of 'normal sugar level'.

As mentioned earlier, patients' social roles and responsibilities cannot be separated from their everyday life in diabetic care. So how individuals prioritize their needs is based on the demands to perform multiple social roles. There are studies which have shown how social responsibilities take priority over attending to the care of diabetes. Drummond and Mason (1990) illustrated in their study how individuals with diabetes living in poor socio-economic conditions prioritized their social and economic needs, such as paying house rent, feeding children, paying electricity bills, over taking care of their health needs. They further argued that such patients' understanding of diabetes and their response to the demands of everyday living was based on logic and reasoning. They also tried to show how doctors' understanding is scientifically determined whereas individuals' understanding of diabetes is socially determined.

Having said that a patient's understanding of diabetes is socially determined, this chapter attempts to capture how individuals try to follow the advice of their healthcare providers on a day-to-day basis. It will further look into how their everyday social needs influence and shape their behaviour in caring for diabetes.

5.1. Social needs vs. Health needs

It is observed that social roles and responsibilities are very often prioritised over healthcare needs in patients with diabetes. These roles are again determined by the socio-economic condition of the family. One could perform better if the required support system is in place. Similarly, everyday needs of diabetes can either be completely or partially satisfied or completely ignored based on the existing support system.

An exploratory study conducted by this researcher in Chennai brought into focus the role of support system and class variation in everyday management of diabetes (Devarajan A., 2014). A 71-year-old Mrs. S, a highly-educated politician, followed a strict routine, scheduled meal-timing, balanced diet and prescribed medicines. When she was busy attending political meetings, her meal timings were tracked by her daughter-in-law, who also drove her to the beach for a daily walk. Despite her privileged status, Mrs. S would sometimes skip meals during political meetings and would enter hypoglycaemic state. She spent Rs. 40,000 rupees in a private nursing home for treatment but the expenses towards investigations and medicines were reimbursed through her health insurance. Contrastingly, a 65-year-old Mrs. L, diabetic for 12 years, used to manage her family with her husband's monthly income of Rs.9000. She would struggle to have three meals a day. If she skipped the meal, she would also skip the medicines. Most of the time, her food would be boiled rice (*kanchi*) or dosa with chilli powder, but on some days, she would also consume vegetables. She was being treated at the government-run urban health centre. In case of emergency, such as fainting due to hypoglycaemic/hyperglycaemic condition, she would be admitted to a private clinic near her place, for which she would have to take a loan from money lender or pledge her only gold chain to meet the treatment expenses.

While the study by Mendenhall E and Weaver LJ (2014) demonstrated experiential, psychological intersections between social experiences, depression and diabetes. The narrative of Maria, a 56-year-old working class woman based in Chicago, USA gives us insight into the above. It illustrates the multiple demands made on a working-class woman whose daily routine involved 'a long travel for work, household and childcare at work, similar

activities after returning home from work affected her care for diabetes. She used to skip her morning meal and hence her medicine because of less time. All her evenings would be spent with her grandson, then eat, spend time to watch TV and go to bed, as Maria says “Every day is like this”. The experience of Maria is echoed by Seetha, a 32-year-old woman based in New Delhi, India who talks about how her persistent physical weakness as well as her depression and diabetes made her feel, think and act towards diabetes.

The concepts of syndemic and chronicity have had facilitated in dissecting the multiple layers of different aspects of life and its intersection with each other. Hence everyday coping is not a single and isolated entity and embodied in social, economic and cultural spheres of one’s life.

5.2. Everyday coping with diabetes

After analysing the overall socio-economic conditions of the participants of this study, it is envisaged that their everyday routine depends on the type and nature of their occupation. This can tell us how much time one spends at home environment or outside it, the nature of occupation, and location of the work place, all of which play an important role in their everyday life and further coping with diabetes. Based on the work pattern, the female participants are grouped into five categories as follows:

Table 5.1: Classification of women based on work pattern

Classification	Work pattern
Group I	A female who works under MNREGA or any other work outside home, or works as an agricultural labour or in an export company, and also does household chores including taking care of the dependents (children /elder adults/ person with special needs)/ caring for livestock
Group II	A female who either works under MNREGA or is involved in farming (marginal) and also takes care of household chores and of dependents
Group III	A female who works in neither MNREGA nor agricultural activity and remains only at home
Group IV	A female who is a dependent elderly adult, with or without complications
Group V	A female participant or the member of the family involved in or retired from government job / professional job such as engineers

Similarly, the male participants are grouped into five categories:

Table 5.2: Classification of men based on work pattern

Classification	Work pattern
Group I	A male who works under MNREGA or any work outside home in any company or one who work as an agricultural labour
Group II	A male either works under MNREGA and also involve in farming
Group III	A male who neither works under MNREGA nor does any agricultural activity, and remains only at home
Group IV	A male who is a dependent elderly adult, with or without complications
Group V	A male participant or member of the family involved in or retired from government job / in professional job such as engineers

This section begins with three case studies of Mrs. R, Mrs. M and Mrs. S to broadly understand an individual's everyday life and her experience of coping with diabetes. These three cases provide insight into the different aspects of everyday experience in diabetes management such as work-related activities, diet, medication, physical activity, leisure, and sleeping patterns. This is presented across caste groups that include the scheduled castes (SCs), most backward caste group (MBCs), backward class muslim (BCMs), backward caste (BCs) and other caste (OCs) groups. The gender and class would be located within and across caste groups as categorized in the method section.

5.3. A widow with three girl children and her struggle between her social condition and diabetes

Mrs. R (Group I), 48-year-old, a widow with three girl children from the scheduled caste group, received no formal education and lives in a small house built under the government house scheme for the poor. She depended on Mahatma Gandhi National Rural Employment Guarantee Act (MNREGA) for livelihood and earned up to Rs. 1800 per month through this work. In addition to this, she had taken up another small job, sweeping and keeping water every morning in the horticulture office close to her village. Through this job, she earned Rs. 1000 every month. She also took care of a cow in her household. She had three daughters, one of whom got married, while the other two were working in an export company after completing their high school education. Their total monthly income was Rs. 4500 each. She had been living with diabetes for three years and experienced hypoglycaemia as well hyperglycaemia and vision problems too.

Often, she did not cook in the morning as she had to reach the horticulture office for work, then feed the cow, and later leave for MNREGA work. She looked for some other agricultural work if she did not find work under MNREGA. As she said:

“These girls (referred to her daughters) leave at 5 in the morning and come back by 4 pm. So, I have to cook by the afternoon. I eat leftover rice from dinner the next morning, otherwise I drink tea and leave for work”(Mrs. R, Aandimadam, 11.09.2015).

Her food intake would determine whether she had medicines or not, in other words, she would often skip medicines (Metformin, Glibenclamide and Vitamin B-Complex) if she did not have breakfast. When she would feel discomfort (giddiness), would rest for some time and then resume work. On some days, she skipped her meal despite the availability of food due to anxiety regarding her elder daughter. Her son-in-law was irregular with work and so her daughter would come to her often for financial support. She also took loans for her daughter’s wedding, and for the delivery of her grandson, trying to repay these gradually. She also worried about her other daughters and their weddings.

Sometimes she would experience giddiness for which she would go to Tirukalukundram Government hospital. After checking her, the nurse would tell her that the sugar level was low for which she had to take medicines and food regularly. She said that due to multiple demands at home she was unable to attend to herself:

“I am trying hard to take care of my elder daughter also. Sometimes she comes home for her illness, at other times she comes for her son’s illness, and she often asks me to take loans for other expenses, which I only need to repay later. Sometimes I would ask my younger daughters to help in repaying the loan. I have to save little for them also, no. If these girls would go for work regularly, then they could get Rs. 4000 per month. But my youngest daughter cannot go to work continuously as she has ulcer and other problems. Her salary is cut but what can we do?” (Mrs. R, Aandimadam, 11.09.2015)

She continued:

“In this situation, I have to repay the loan I borrowed earlier. Sometimes, I borrow loans for which I need to repay every week, which again is a challenging task. In all these tensions, where would I think about my diabetes, food and medicine? Most of the time, I would have ‘kanchi’ (boiled rice with water) with ‘uuruga’ (pickle) or onion to bite. When the nurse would advise about regular food, medicines and all, I would think that I should follow

that properly but later I would end up with the same stories, same worries at home, leaving behind my diabetes. The doctor would ask me to do blood test.”

“Sometimes when I become seriously ill and am bedridden, that is when my blood sugar test is done. My daughters would also show some concern then, giving me medicines and food regularly, reminding me about medicines. In these three years, I got admitted twice, once because I had low sugar, and another time because I had high sugar. Nowadays, I am trying to take food and medicines regularly but when family worries increase, my thought about diabetes would be hidden somewhere” (Mrs. R, Aandimadam, 11.09.2015)

Earlier, she used to drink many cups of tea before eating a proper meal at lunch time. Her meal consisted more of rice and ‘karakolambu’ or tomato curry. Sometimes, she cooked leaves from a drumstick tree that grew outside her house. She would buy vegetables or green leaves from vendors near her house, and only sometimes visited the local market to buy vegetables. She would try to prepare sambar weekly once (split peas with vegetables such as drumstick, carrot, brinjal or plantain). Her daughters would insist that she prepare idli or dosa on some days when they used to prepare coconut chutney. She also prepared fish curry for her daughters once in ten or fifteen days as fish was abundantly available and vendors also sold it in her village. She cooked beef when all her daughters and son-in-law would come home on special occasions. She herself didn’t eat beef but she ate fish if there was enough for everyone. She prepared extra curry when she cooked fish so that she could keep it for the next day to eat with rice.

She said that she felt exhausted after work but that she could not rest after returning from work as she had to attend to household chores like cooking and feeding the cow with rice husk and water. She would eat her first meal around 3 or 4pm at least weekly once or twice. Then, she would take the cow for grazing when her daughters reached home. Later, by 7pm, she would watch TV and fall asleep sometimes. Later, around 9.30pm, she would have dinner but would often forget to take her medication. She had difficulty falling asleep because of her anxiety regarding all her loans and the future of her daughters. Then, she would fall asleep around 12 or 1am. She added that her nap around 7 pm was very good as would fall asleep out of exhaustion without thinking about anything.

5.4. About a young widow (Class I), who lost her job due to diabetes, and her everyday life with diabetes

Next, we will read about a young widow who lived alone, struggling to cope with her diabetes every day. Mrs. M (Group I), aged 40 years, is also a widow from scheduled caste group, who received no formal education and lived in a thatched roof. Like Mrs. R, she too sought employment under MNREGA, earning up to Rs. 2000. Earlier, she was working in a pen-manufacturing unit and earned around Rs. 4000. She got diabetes when she was 37 years old. She had lost her regular job due to giddiness at work place (due to hypoglycaemia) a year after the onset of diabetes. She also had asthma, which made agricultural labour an unfeasible option, especially when working with water-intensive crops like paddy. She would do other works like weeding in groundnut field and harvesting. Sometimes even harvesting paddy would cause trouble in breathing. So, she would seek other kinds of work. She also stated that she could not work in the sun after she got diabetes. As a result, her income started to drop due to her illness and she now depends on her daughter often for her expenses.

Like Mrs. R, she also had the habit of cooking after she returned from work in the noon or in the evening. Sometimes, she would not cook at all and remain empty stomach all night. She felt hesitant in going to her daughter's house, thinking her visits would cause her daughter's in-laws to look down upon her. But there were days when she wished her daughter would invite her for a meal. In contrast, when her daughter and son-in-law visited her, she would cook two meals for them in single day. She said:

“It is only for me I need to cook, my husband also left me (died 2 years ago), I wanted to build my house and you can see this thatched roof, which leaks during the rains, my husband used to say that we would build a house once our daughter has been married off. But after few months of my daughter's wedding, he fell sick and died (of TB). Now I am alone here, I cannot sleep at the night and I have breathing problem every day. Some days, I rest for the whole day because of this asthma problem. If my daughter gets to know of my condition, she brings me 'kanchi', otherwise I take tea two or three times that day”.(Mrs. M, Mullikulathur, 27.11.2015)

I started munching betel leaves when I had a severe cold, and now I cannot stop. Sometimes, after having tea in the morning, I started munching betel leaves, skip my breakfast and also skip my medicine. I would go for NREGA work and come back, clean the house, the utensils, and then cook rice and 'karakolambu', and I would have it during evening and night.

If there is left over from dinner, I would take it in the morning. I would buy vegetables sometimes only and most of the time I would make 'karakolambu' only". (Mrs. M, Mullikulathur, 27.11.2015)

She used to visit Tirukalukundram Government Hospital to get her sugar tablet (Metformin) regularly and blood test, the latter rarely. She said that she would experience low sugar most of the time and she would take little sugar and lie down for some time. She would also visit the private doctor for her asthma and she would spend Rs. 118 on her inhaler every month, sometimes buying two inhalers. Her son-in-law would also buy her the inhaler. She used to worry about being lonely and poor housing condition, saying she would try to build a small house through government schemes. She also added that she would have taken widow pension (of thousand rupees) but she could not avail her benefits from the Public Distribution System if she would avail widow pension.

5.5. A woman with two differently-abled children – a family's struggle for livelihood

Now we will turn to the case of Mrs. S, whose everyday life experience is much varied from others, complicating her diabetes-related problems in the long run.

Mrs. S(Group I), a 40-year-old woman, belonged to scheduled caste group. She was illiterate, married, living in a thatched roof with her husband and her visually and mentally-challenged older son. Her second son was also visually-challenged and was studying in Chennai. Every day, Mrs. S, would wake up early in the morning, pray for some time and then start doing her household chores, such as cleaning the courtyard, utensils and then start firing the wood to cook. Meanwhile, her husband would bring little milk for coffee after selling a litre of their cow's milk. Then, she used to prepare coffee and give it to her son and husband and then cook rice and some side dish mainly 'karakolambu'²⁶. On some days she prepared Idli (rice ball made by steaming rice batter) and either tomato chutney or tomato chilli paste or 'saambar'²⁷. She narrated her everyday routine as follows:

"I finish cooking quickly, then I bathe my son (16-year-old, mentally retarded, visually-challenged) and feed him. Usually, he does not eat and spits the food out. Sometimes,

²⁶Made by tempering onion and tomato in oil, adding tamarind juice, chilli powder and salt, and boiling it with or without other vegetables.

²⁷ Split pulse boiled with onion/tomato, chilli powder and salt; vegetables maybe added with tamarind juice. Once the vegetables boil, it is tempered with mustard and curry leaves.

when he likes the food, he will eat it without a fuss. Later, I will take my medicines, try to do other work, and I eat... then I will take another medicine. It is usually 9 to 10 am in the morning when I eat and leave for work. My husband takes care of my son till I come back from work. When my mother-in-law was alive (she died 2 years ago) she used to take care of my son, my husband also used to go for work and earn around Rs.350 to Rs.400 per day. He was working in a mining company. They started giving work to people from other states, who would work for less 'coolie' (wage) than the local regular labourers. Hence the local people got affected and are getting lesser wage than earlier. The company also ignored the locals as it was getting people from other states for cheaper wages. As someone needs to be there to take care of my son, my husband would remain at home to take care of my son. He would also take care of a cow, which we bought through a loan provided by the government. In the morning, he would take it out to graze, and sometimes in the afternoon, when I came back from work. We do not have land and all, we cannot go to others' land also for grazing, so we used to buy 'vaikkapullu' (rice straw) to feed the cow”(Mrs. S, Karumarapakkam, 06.10.2016).

She continued:

“I used to manage my family with the money I earn from MNREGA and the amount (Rs. 2000) which we receive for our sons (one is visually and mentally challenged, and the other one visually challenged. We also have to spend on our second son's transportation and another hostel needs as he is studying in Chennai. We eat rice that we get from Public Distribution System (PDS) and when it gets over, I buy PDS rice for Rs.10 per kg from others and polish it for cooking” (Mrs. S, Karumarapakkam, 06.10.2016).

It was also observed that she used to take up MNREGA work from her relatives who would not work for 100 days and would give some amount to them in turn. For example, if she would work for 10 days she would get Rs.2000, from which she would give Rs. 500 to the person from who she got that work. She also did sanitation work (collect garbage from each household and clean the streets in the village) as part of MNREGA. She would also go for agricultural labour when work was available.

When working under MNREGA, Mrs. S usually came home by 2pm and would eat lunch. Then, she would do the remaining household chores like washing clothes, cleaning utensils, cleaning the courtyard and preparing tea for everyone. She would not buy milk when she did not have money. But when her second son came home for holidays, she had to buy at least

250 ml milk, along with which he also wanted biscuits, which Mrs. S could not afford on all the days. So, sometimes she had to deny his request for biscuits with tea. She narrated her situation as:

“We cannot afford for biscuits all time, and if we try to buy it when money is there, this will become a habit. We poor cannot afford that, you know. We both (my husband and I) also tend to take biscuits along with tea when we buy it for our children, so hence try to avoid making a habit out of it.” (Mrs. S, Karumarapakkam, 06.10.2016).

Later, around 6.30 to 7 pm, she would prepare food, feed her son and serve her husband and at last she would take sugar tablet and then eat herself. Her son would remain silent when watching TV, so she would leave it on TV for his sake. They would sleep around 10 pm. Her son would not sleep most of the time, making noises till about 1 or 2 am, when he finally slept. He also used to walk inside the house and hit himself against the wall or on the door. Hence, she used to be awake until her son slept. She would soon fall asleep out of exhaustion some days but on most days, she had to keep a vigil late into the night.

She admitted that at present her body is relatively strong and can bear all the odds but this physical exhaustion, sleeplessness, and stress due to financial distress might affect her health later.

Mrs. M.B. found it very difficult to handle the co-morbid condition of TB. Mrs. M.B. was 39 years old, had studied up to 5th standard, was married, worked as a landless labourer, and lived with her husband, son, daughter in-law and a grandson in a pucca house. She had diabetes for the past six years. She used to work under MNREGA and also made money out of rolling beedi. The doctor advised her not to do beedi-rolling as it might aggravate her sugar condition, so she left it two years ago. Her husband is a tailor, her son an auto rickshaw driver, and her daughter-in-law, a house wife.

Mrs. M.B.'s day would start around 6.30 am by cleaning the portico and then the house. Once she was done with cleaning utensils, she would get ready for work under MNREGA. Meanwhile, her daughter-in-law would prepare the meals. She would take insulin and then breakfast (mostly idli/sambar). Her niece or her daughter-in-law used to give her insulin shots every day. She used to take care of her grandson for some time until her daughter in-law finished up work, and then Mrs M.B. would leave for work. She would never pack lunch and carried only a bottle of water. She said if she felt hungry in between, she used to take water

only. She used to have lunch once she came from work around 2.30pm. Then she would sleep for some time. Later she used to visit her sister and mother in the next street. If she was not allotted MNREGA work, she spent time with her grandson at home. She mentioned that she would count her visit to her sister and mother as her walking (which would take minimum 10 minutes). Some days she used to visit them two times.

She narrated how she had fallen sick and was diagnosed with TB:

“I had fever continuously and I went to the government hospital, then the private clinics at Tirukalukundram, but it was of no use. The doctor at the private clinic ran a number of tests, and then referred me to the Chengalpet Medical College and Hospital. There they admitted me as an in-patient, treated me for few days, and tested me for TB. Then, they started my treatment for TB and reduced my sugar level with insulin and asked me to continue insulin till TB would get cured. The doctor and nursed advised me to have healthy food and the nurse said I must consume ‘beef’ and ‘egg’, so that my TB would get cured faster”(Mrs. M.B., Kamaraj Nagar, 29.09.2015 and 02.12.2016)

She continued:

“Sometime I get confused with their advice as when I go for diabetes treatment they used to tell not to have non-vegetarian items like mutton or reduce non-vegetarian items. When I used to have food at home, I would confuse myself ‘what to have and what not to have?’. I clarified from the nurse, who told me during my subsequent visit that till my TB is cured, I can consume all these food items adequately. I started taking food as per their advice. My TB also got cured within 6 months, but my sugar level was not decreasing, so they asked to continue taking insulin”.

The cases of male participants will add different dimensions to everyday life and coping with diabetes.

5.6. A man with dual burden of diabetes and TB, and his story of everyday-coping

Mr. P(Class I) is a 41-year-old, who studied up to 9th standard, and worked as a driver in the coal mines, earning Rs. 1500 for two days of work. He lived in a pucca house with his wife and two sons. His wife worked under MNREGA and also looked after the family’s cows. His sons were studying in 11th and 9th respectively when the interview was conducted.

Mr. P had been living with diabetes for 7 years, and being treated at RUWSEC hospital, taking Glibenclamide. Six months ago, he was diagnosed with TB, for which he was taking treatment at Chengalpet Medical College and Hospital. He was also asked to take Insulin then as his sugar was not under control. He said that the doctor also asked him to get a single solution (human mixtard) outside as they used to provide two insulin solutions, which he had to mix and inject and it was easier injecting one solution.

His routine started with milking the cows, which he would sell in the cooperative milk society, keeping some milk aside for domestic use. Around 7am, he would take tea and then take medicine and breakfast around 8.30 am. Then, he would leave for work, as he had to be there at 9.30am. He used to drive a vehicle used for collection and disposal of mining wastes. By 11am, he would get a tea there. He mentioned that he would have it with sugar only and that he never took the risk of informing people at work to provide him tea without sugar. Then he would go home for lunch at 1 pm. For all three meals, he would eat rice, while on some days, his wife would prepare vegetables for lunch. When he was being treated for TB, the nurse told him to have eggs and peas, so he used to have an egg in the morning and green peas/green gram in the evening. He was at home then. He started working in the mining company six month before the interview; before that, he used to drive when people called him on a need basis. Now he would spend around two hours during his lunch break at home and he returned to work at 3pm, had tea at 4.30pm, and worked till 7.30 pm. After he resumed work, he also stopped his routine of eating something in the evening, returning home only in time for dinner. Some days, he used to have ‘chapathi’. Then, he would go back to work at 9.30 pm. Then after 12.30 am, work would ease down. Around 7.30am, he would leave for home to eat breakfast. A similar routine would continue till 7.30pm that evening and then he would be relieved for the day. He would have dinner and go to sleep. If he would feel better he would go for work the next day, otherwise he would rest and continue with work the day after. When he was asked about walking (physical activity), he replied:

“I should go for regular walk but I don’t. I had changed my food habits to some extent and take medicines regularly. I am not alone... I have to take care of my family also. I have to do bit of work at home and then go for work outside. This is the reason I could not spend time for walking and all” (Mr. P, Karumarapakkam, 29.03.2016).

He added that his blood sugar used to be normal before he got TB. But after, that fasting level rose to 140 or 150. When he was taking insulin, the fasting level was 100 or 110mg/dl.

From the above case, it can be understood that an individual's routine, nature of work and domestic responsibilities influences everyday-coping with diabetes.

5.7. An unemployed man with diabetes, TB and Depression and his everyday-coping

Now, we shall look into the interaction of TB and diabetes in Mr. M's life. Mr. M, 48-years-old, studied up to 10th standard, was working in Kalpakkam (filter/exhaust line cleaning) on contract, but had stopped working at the time of interview. One of his sons had completed his D.C.E. (Diploma in Civil Engineering), was working in a private company and was earning around Rs. 10,000. The younger son was still in college, while Mr. M's wife used to work under MNREGA.

Mr. M, affected with diabetes a year ago, also got diagnosed with TB two months ago. He was getting treated at Government Hospital, Tirukalukundram. After he got TB, he started taking treatment for diabetes at a specialty hospital. During the diagnosis of TB alone, he had spent Rs. 27,000. He paid that amount by pledging his wife's gold chain. He felt TB would create stigma for him and hence he requested one of his relative who used to work at government hospital to collect TB drug for him. He stated:

“It would be bad if others come to know about my TB condition and hence I requested one of my relatives who is a staff at the government hospital to collect and give my medicines in private. I do not go to that clinic in person. I also came to know that diabetes need to be controlled to get cured of TB.”(Mr. M, MettuEgai, 02.03.2016).

He further narrated his worries about his unemployment status as follows:

“I am not going to the job and I feel that I became a burden to my family. My son is working on contract only and he gets Rs.10,000 per month. We do not have agricultural land also. But we managed to raise two cows. If my wife would go to MNREGA work, I will take care of these cows after having breakfast, i.e. graze them in the nearby waste land and then feed them water. Some time I keep planting some vegetables like brinjal, plantain, country beans in the backyard. I also do weeding. (I can say this is a small kitchen garden, where we get enough vegetables for cooking some days) Then I will rest for some time probably around 12 to 3 pm as it will be too hot then.” (Mr. M, MettuEgai, 02.03.2016).

Then, once his wife came back from work, they both would eat lunch. He expressed that he could not have a deep sleep. He would keep on thinking about his dependency status raised out of his ill-health. As he expressed, this is how he felt about his present status:

“Doctor also told me that I need to take care of my kidneys too. My wife and sons are concerned about me, they take care of me well in terms of food, treatment and everything. But I feel very guilty as I became a big burden to them now, I am not earning also, more money is required for hospital expenses. When I was hospitalized earlier, they paid by pledging my wife’s gold chain. When that amount was not enough, she also borrowed money from her relatives. If I get cured of this TB, then I will try another job.” (Mr. M, MettuEgai, 02.03.2016).

On one hand, his engagement in several activities illustrates his self-sufficiency and self-worthiness. But on the other hand, his engagement in these activities made him think more about his dependency, his sense of self-worth. This, along with other symptoms like sleeplessness, reveals his state of depression.

5.8. Irregular routine and everyday coping with diabetes – A case of hospital servant

Mr. D (Class V), a 45-year-old male from the scheduled caste group, studied up to 10th standard, and was working as a “servant” in a government hospital, earning around Rs. 17,000 per month. As his work place is in the neighbouring district, he used to stay in the hospital quarters, visiting his family once a week in his village where his wife and three children live. His wife worked as a gardener, earning around Rs. 4,000 to Rs. 4,500 per month, based on the number of days she found work. His two sons and one daughter are studying in standards 11th, 10th and 8th respectively.

He had been diabetic for three years. Meanwhile, he also developed hypertension and vision problems. He used to help a Siddha doctor at the hospital, distributing token to patients and sometimes shifting patients in the ward. The doctors and nurses would expect him to be available for all kind of assistance. An important part of his job was body dissection (post mortem) in the mortuary. Given the difficult nature of the job, he used to consume alcohol whenever he assisted in a post-mortem examination, not only in the hospital where he worked (Gummidipoondi) but also in the Ponneri Government Hospital where he was often called for such jobs. Many accidents used to take place there, hence he and his colleague would often go there. He had been working in the government hospital for 10 years now. Three years ago, he

was diagnosed with diabetes. As he was working there in a health facility, within a few days of his symptom, he informed the doctor, who advised him to do a blood sugar test immediately. His blood sugar was 425 mg/dl then and was confirmed the next day with fasting and post-prandial blood sugar tests. Since then, he started taking oral hypoglycaemic agent. Simultaneously, he was diagnosed with high blood pressure and had anti-hypertensive agent added to his medication regimen.

As Mr. D used to live in the quarters within the hospital campus, he would get job calls during the night too in case of emergency. He would get job calls minimum three times in a week. His work timing was from 7am to 12.30pm and 3 pm to 5 pm in the evening. He used to wake up by 3.0am, go to the hospital ward, and then go for walking, buying fresh fish from the market on some days. Then around 5 am, he used to cook and reach the hospital around 6.30am. He used to prepare Lemon rice, curd rice, vegetable rice or fish curry. When he developed a vision problem, he started taking more vegetables. As he had to reduce his sugar to get treated for his vision problem, he started following proper diet on time. He used to go for lunch around 1 pm to 2pm. If there were a lot of patients, he would have to postpone lunch. Some days, he could not cook due to time constraint and would buy outside food. He never used to have any snack or meal in between. He would take a tea around 4.30pm and leave from work by 7pm only. Then, he would reach the quarters and freshen up. If there was food left over from lunch, he would have that for dinner. He would always prefer to buy from outside for dinner. He also used to visit the hospital after dinner sometimes and have a round of conversation with the staff working there. He would sleep between 10:30 pm and 11 pm. He used to cook fish often earlier as it was available abundantly but because of his high sugar and eye problem, he reduced fish consumption later. Now, he would consume non-vegetarian food only during weekends when he visited home. He used to call his friends home and consume alcohol with them, leading to some friction with his wife. He used to sleep only for 4 hours during week time and hence he would sleep longer when he was home. Earlier, he always had little high sugar and said that he could not satisfy his wife in “family life” (sexual life). But later he started reducing his alcohol and meat consumption and would try to increase his sleep duration so he could live his life happily.

He also said that he could deal with any family problem, and that his discomfort lay in post-mortem examination work, due to which he could not give up drinking. He reported that his last blood test had 124 mg/dl fasting level, and 140mg/dl post prandial level.

5.9. Old age, family dynamics and coping with diabetes and other co-morbid condition – A case of an elderly couple

71-year-old Mr. SH (Group V), a retired teacher, followed a strict schedule for each activity daily. He would wake up around 5.30 am, do simple exercises, including breathing exercises, take a bath, have coffee and then go to the temple, where he was involved in managing temple activities (“Dharmakartha”). He said he would walk for several things there and also do circumambulation, which would suffice for his day’s physical activity. Then, he would go back home around 9am, when his breakfast would be ready. The breakfast would be idli or dosa –with different grains or mixed flour with chutneys made of onion/coriander/curry leaves/ sambar. He would take one hypoglycaemic medicine from allopathy and another hypoglycaemic agent and anti-lipid agent from a Siddha practitioner.

Mr. SH said his wife was also diabetic and that he would tell her to accompany him to temple for a walk. She, however, preferred going in the evening, as going in the morning would interrupt her cooking and household work schedule in the morning. Then, after breakfast he read until lunch. Meanwhile, he would be served one tumbler of butter milk. Then, after lunch (comprising of rice, sambar/any other curry with vegetable or fish curry on Sundays) he would sleep for some time. Upon waking up, he would go to the market for shopping and then sit and watch TV news or other programmes with his wife. Then around 7.30 pm, she would prepare wheat dosa or chapathi, which they would eat with same curry and vegetable which was prepared for lunch. He would visit the health facility (Institute of Siddha) twice in a month. He would also visit Chennai to collect monthly rent from his house tenants. Mr. SH had a schedule for everything. He also used to accompany his wife when her turns for hospital would come. She started taking treatment of diabetes from the nearby Primary Health Centre because they found private hospitals too expensive, and she would also visit Siddha Institute along with her husband to get medicines for her arthritis problem.

Few months back, Mrs. SH had undergone cataract surgery and they stayed in their son’s place till her recovery. But their daughter-in-law was not very welcoming, telling her mother in-law to prepare food for the elderly couple separately. She then asked her father-in-law to pay the electricity bill, buy groceries and the like. While there, Mr. SH gave three thousand rupees separately for their food expenses. Although he was drawing a pension of Rs. 20,000, he had had taken a loan for the construction of their house. He also had to save some money

for his granddaughter's puberty function then. But his daughter-in-law's behaviour made forced them to return to the village. He added:

"I never disturbed my son in case I had to give gifts or money to his daughters during ceremonies and family events. I constructed a house for him in main town. I gave more than half the amount I got from the sale of my agricultural land to him for his business only. Still my daughter-in-law would want to take everything from me and assume that I should not keep anything with me or to spend on my daughters. In this situation, my blood pressure would rise some times. I would try to manage it" (Mr. Sh, Suradimangalam, 13.10.2016)

5.10. Every day (routine) Activities

The everyday (routine) activities vary from individual to individual. But there are some patterns which are observed as being similar across individual experiences. From the above case studies, it can be seen that the routine activities performed by the individuals, especially women, remain similar with regard to household chores. The quantum of work varied from Group I to Group II and to Group III.

For example, Mrs. AL (Group II), 40-years-old, belong to scheduled caste, studied up to 8th standard, was married, worked under NREGA, would work in the family farm (an acre of agricultural land), and was also involved in chit-fund business. She used to take care of cows at home while her husband used to take care of farm activities in their agricultural field. Her routine would start early in the morning by 4.30am. She used to cook early as her daughter who would start from home early, around 5.30 am to 6am, to reach her college on time. She would complete preparing both breakfast and lunch in the morning itself. Then, she did other chores such as cleaning the portico, collecting of cow dung and cleaning vessels.

Meanwhile her husband, who used to collect milk from the cows, would keep some of it for their tea, and sell off the rest in the milk co-operative society. After this, Mrs. AL would prepare tea and serve it to everyone. Then, she would go for bath, take her medicines and eat. If NREGA work was allotted that week, she would go to work, otherwise she remained at home. She would fetch water with the help of her son. If she would go for work, her son would take care of fetching water entirely by himself. They used to fetch enough water to suffice for six people in the family and also the cows and calf (five in all). After fetching water, she would return home, do the laundry, eat and sleep. After a short nap, she would feed

the cows and would start cleaning inside and outside the house. On some days, her husband would prepare tea. As she expressed:

“He started having more tea after he left alcohol. I had a bad phase earlier because my husband was kind of an alcohol addict. Those days were like hell. If he would have continued, I might have gone to my mother’s house. I would not have lived with him and raised my children. Then we (she and her children) made him to go to a temple to relieve from this alcohol habit. He promised in front of the God that he would never touch alcohol. But if he would touch he would experience blood vomit and might lead to death also.” (Mrs. AL, Karumarapakkam, 25.03.2016).

She continued:

“This is the reason he is scared to touch alcohol now. Our two sons studied B.E with loan only. We are paying back that loan. Now this is what my problem is... My elder son had got a job in a TV channel. But he cannot sustain that job. He does not have that capability to be there. (Her son also said that he is not that smart like the guys in the city and he will have to find a new job)” (Mrs. AL, Karumarapakkam, 25.03.2016).

From the above narrative, it can be interpreted that despite resisting the violent behaviour of their husbands, these women carry the memories and thoughts of the same all through their lives. In other words, those thoughts remained as unhealed wound. This is not only the case of Mrs. AL but also Mrs. K (aged 65 years), belonging to backward caste group. She shared that she could not sleep during night as she would recall those memories of her husband’s torture (physical/mental). She also pointed the same as an important reason for uncontrolled sugar (300 or 400mg/dl) and further onset of foot ulcer and cardiac problem. The chronic accumulation of emotional stress, physical stress and worries over self-worthiness, self-respect/dignity further worsen the diabetes condition. These bad experiences had also contributed for their strength to go through any kind of hardships in life from any other source other than the husband.

“When you are experiencing something very problematic for long period, you become habituated to it, but the emotions will be suppressed somewhere inside” shared Mrs. R, Perumbedu (23.03.2016), who also shared her experience with her abusive husband as given under chapter 3(pp.18).

It was also found that in some cases that the extension of support from family was very helpful, such as help in fetching water by son as found in case of Mrs. AL, or that most of the work in the field was handled by her husband. She used to take more tension on money

collection in the chit-fund business. Her son only used to accompany her, pick her and drop to places wherever she wanted to go in relation to this business. But there are several women who expected such help/support from family members but would never get it.

Now Mrs. K, 60 years of age (Group II), used to be very active all through the day. She lives in a joint family with her husband, daughter, grandson, his wife (granddaughter-in-law) and great grandson. She used to start her day early in the morning, cleaning the portico, collecting cow dung, feeding the cows water and paddy husk, and then collecting milk, which was given to Aavin Dairy company, which used to collect milk from the producers for money. They used to disburse the money every weekend. Then, she would return home with some milk for their use, mainly for her great grandson. Then, she would clean the cooking utensils (sometimes her daughter would do it before she leaving for her gardening job), meanwhile her granddaughter-in-law would prepare the meals. She would take coffee if the food wasn't ready by then. Otherwise she would take medicine and have food. Then she would go to the field (half acre), where she would cultivate mainly grass to feed the cows or she would manage with buying feed outside. They used to give them paddy straw/husk, or Mrs. K would cook rice to feed the cows when the feed was less.

Later, she would rest for some time and would take lunch if she felt hungry then. Otherwise she would take the cows to the field for grazing (for 1 to 2 hours) before collecting milk in the evening. Then, she would clean the house and portico, and collect the cow dung in the cow shelter. She would again collect milk from the cows and give it in the Aavin milk collection centre. Later, she would prefer a tea and spend some time with great grandson. Around 7 pm to 7.30 pm, she would take medicines, eat food, and fall asleep soon after.

Different from others, Mrs. V (Group III), 45-year-old, from scheduled caste, followed a very different routine. She said that she also wanted to go for work like others. But her husband instructed her from the first day of marriage that women should not do jobs and should remain at home, taking care of home and children, while the men should work and earn to take care of the family's economic needs. But she shared her wish to go for a job as follows:

“I also felt like going for outside work and I completed 8th standard, that too in English medium. I had also got an opportunity to work as an anganwadi worker, but then too he did not allow me. What to do, this is women's life. If you are born as a woman, you need to face all these things”. (Mrs. V, Karumarapakkam, 25.03.2016).

Like Mrs. AL, she used to prepare food first and then complete other activities. Her daughter (a college student) used to help her in cooking rice and sometimes sambar if she fell sick and needed to rest. As she suffered from unhealed foot ulcer for the past seven years, she would fall ill sometimes. She used to wear slippers when she would walk in the mud. Still she would perform all the household chores including fetching water, watering the plants, cleaning utensils and washing clothes. She would also go to Tirukalukundram market everyday to buy vegetables and other food items.

37-year-old Mrs. AD(Group II), belonging to backward caste group, said that she usually started her day with kitchen work - once she woke up she was supposed to care of her husband's needs as he would be the first person to leave home early in the morning to sell tender coconut in the neighbouring town of Kalpakkam. Once food was prepared, she would pack it for her husband and for her children, who would start early as no bus facility available from their village to their school. The children used to walk up to the neighbouring village (more than a kilometre away) where they would take the bus or shared auto rickshaw to reach their school, which was located in the town of Tirukalukundram. She used to finish cooking by 7 am and then start cleaning the house, cleaning utensils and washing clothes. She would have breakfast around 11 am after completing all the work.

She would rest for some time and then stitch clothes (such as ladies' blouse). She would try to have lunch by 3pm but would skip it if she was not feeling hungry. Her children would reach by 5 pm, around which time her father-in-law would bring milk. She would prepare tea and served everyone. Some days she would also prepare some snacks. When I visited her, she prepared pongal with 'pathaneer' (a sweet beverage extracted from palm water) and all the family members were all having it. She offered it to me as well, and I savoured its sweet taste. When I asked Mrs. AD about her sweet consumption, she said that she would restrict taking sweet items. She added very little jaggery to this pongal and hence she tasted it a little. This informs us that people have their own logical reasoning behind each and every aspect of diabetes.

5.11. Family arrangement and sharing of work at the household level /agricultural field

Mrs. M (Group II), from most backward caste, Mrs. AD (Group II), from backward caste, and Mrs. UM (Group II), from other caste (OC) – all three have similar kind of routines from preparation of food to partake in their agricultural activities. Mrs. UM and Mrs. M were not helped by family members in any single activity. Meanwhile, Mrs. AD lives in a joint family,

and both her father-in-law and mother-in-law help in taking care of their cattle, and also work under NREGA. So, she would hand all other household chores including caring for children. During her leisure time, she would do tailoring. Whereas in case of Mrs. UM, her husband used to go out of the village for work and would come home once a week. She used to take care of cows, agricultural activities like paddy irrigation, and so on. Sometimes, she had to irrigate the field in the evening after sunset. She would think of employing someone for the job but would change her mind because she would have to pay Rs. 1,500 per month only for irrigation, or the payment would be based on an hourly basis. As her family is in debt, she would think twice before spending for anything. As she expressed:

“I could not afford for anything like that, I need to think twice before I spend. We are indebted towards money lenders for our agriculture, my daughter’s education and we need to pay back slowly.”(Mrs. UM, Periyakattupakkam, 06.04.2016).

Whereas in case of Mrs. M, her husband would take care of agricultural activities but he would expect her to work on the field with other people for sowing and weeding. She used to cook and serve them. Whereas Mrs. UM would ask her husband to take leave from his work (helper in a mechanic shed) when there would be more work in the field. He also would take leave with loss of pay.

In case of Mrs. L (Group I), 60-year-old, we can see a different living arrangement. Her routine starts like others, if NREGA work would be allotted, she would finish her household chores, have food and medicines, leave her grandchild in the anganwadi and then she would go for work. As her husband was affected with paralysis, he could perform very few activities. She would serve him too and ensure he took medicines before leaving for work. Her son had fractured his hand. He could perform activities with that hand but slowly. Hence her daughter-in-law would travel long to reach her work place (a hospital) where she used to do a house-keeping job. She had to leave early in the morning and hence she asked them (Mrs. L and her husband) to live with them mainly to take care of the kids. Mrs. L used to take care of everything at home including cleaning the food items. As she and her husband both of them were affected with diabetes, she would try to buy wheat from PDS every month, clean it and grind it into flour in a rice mill at the main town. Whenever she could spend time for this, she would. This flour would not be sufficient and hence she would also buy ragi millet and prepare flour the same way. She used to prepare either dosa or adai with onion and green leaves, which she felt was healthy for both her and her husband, serving the same to her

grandchildren in the evening. Her daughter-in-law would reach home around 4 pm to 5 pm and she would take care of dinner preparation. She expressed that her daughter-in-law struggle to get meagre wage (Rs. 3,500to Rs. 4,000) per month, and she was never involved in agricultural activity either. “But we could not get job from agriculture, you know. My son used to go for NREGA work only because of his hand problem.”

5.12. Diet (balanced) and Medicines

Diet and medicines go hand-in-hand in case of diabetes management. From the first three case studies (Mrs. RU, Mrs. M, Mrs. S – Group I), it was seen that dealing with food itself is a big deal in their everyday lives. There was a considerable difference in one’s struggle to have three square meals a day compared to a balanced diet. In case of few others such as Mrs. K (Group III) and Mrs. C (Group III), food (diet) would be available but they could not have it on time. The preparation will be done for every three meals with addition of fibres in the form of vegetables /green leaves.

For instance, Mrs. K (Group III), 65-years-old, living with diabetes for 38 years said that every day, she would take care of kitchen work and her daughter-in-law would work in the agricultural field. She would always prepare food for her grandchildren, who used to leave early from home to school. After giving them breakfast, she would pack their lunch, prepare coffee for everyone, and she would take some herself without sugar. She said that she used to take tea several times a day. Then, she would clean the utensils, ensure that everyone had enough for their breakfast, take a bath, do her pooja and then have breakfast, by which time, it would be 10.30am to 11am. She added that she used to wait for her daughter-in-law to return from the field and eat along with her.

Similarly, lunch time and dinner would also be delayed, as she served everyone - her husband, her son, her grandchildren - and then she would sit to eat with her daughter-in-law. Despite preparing vegetables and all, some days she ended up eating rice and rasam only. She shared that this happened because her mealtime would have passed then and she lost her appetite. Her son would buy all the vegetables she asked. He used to bring more bitter gourd and ate lot of it as he had crossed forty years, and suspected that he might get sugar too. But his wife was very confident that because he was physically active, being involved in farm activities all through the day, he might not get diabetes.

She mentioned that her mother-in-law (Mrs. K) used to forget taking medicines sometimes if she would feel much hungry. It was also observed during the field visit that Mrs. K would

wait for even an hour to ensure that everyone had their meals (breakfast/lunch/dinner) in the family and only then she herself would eat. She would drink tea if she would feel hungry before everyone finished eating.

Whereas in case of Mrs. C(Group III), who experienced acidity and recently underwent surgery for hernia, always complained of indigestion. She used to take insulin, anti-hypoglycaemic and anti-hypertensive agents, and also anti-lipid drug. But her blood sugar would come above normal. She said that she used to go for a walk earlier, but she stopped when she had hernia operation. She said would start walking again.

Mrs. AL (Group II) mentioned that she used to have food on regular time, reduced her over-consumption of non-vegetarian food, stopped eating beef and would take only chicken as per doctor's advice. She said she used to sleep around 8 pm to 9 pm in the night immediately after dinner.

The only drawback in her everyday management of diabetes which she regretted was forgetting to take medicines, and so, on some days, her daughter or son would check on her for that.

While Mrs. V (Group III) shared that she used to take 9 to 10 biscuits in the morning and that would serve as her breakfast. She shared that she could not have spicy food because of ulcer in the feet (she believed that excessive consumption of red chilli, which was added to the preparation of 'karakolambu', would aggravate her ulcer) and hence she used to prepare 'sambar' most of the time with a minimum of two vegetables. She shared that her daughter would not have complain against anything and would eat anything that was prepared because her first concern was Mrs. V's health. As she shared:

"I would not prepare dosa, Idli and all. But my daughter and even Deviappa (her husband) would not mind the food items and varieties. But he used to bring fish /beef during weekends or whenever he came back from his job (lorry driver). I would prepare it for them. Earlier I used to fry and eat. But now I take only gravy and give them fried preparation if they wish. My son is here only but he lives separately with his wife. Within a few weeks of marriage, she took him to live separately. I could not tolerate that. When I would think about them, my daughter and son, I could not eat properly. But my daughter has no problem. She studied B.A., B.Ed, and a teacher now, so she's settled. I educated all my children well. My

son too studied Engineering, you know. I got a loan for his education. I used to manage everything with whatever he would give me. I spent Rs. 2 lakhs for my son's wedding. I got loan for that also. But my daughter-in-law burdened me a lot, saying I took her gold necklace. I did promise to God I did no such offence. She wanted to live separately and that is the reason she did all these, she accepted with her husband. But that incident remained in me as an unhealed scar”(Mrs. V, Karumarapakkam, 28.09.2015 and 25.11.2016)

She would drink bitter gourd juice twice a week and stopped taking oral hypoglycaemic agents prescribed by the general practitioner in a private clinic.

Whereas Mrs. M (Group II), from most backward caste, faced challenges in everyday coping because of her husband, mother-in law and co-sister. She used to cook every day at home. Her husband used to eat at his mother's house. Some days she would waste whatever food she cooked, or else eat leftover food prepared in the morning for dinner. Someday, if she did not cook for him, he would ask him to serve food, then problems would arise. She said:

“My mother-in-law and my co-sister would create any problems for me and spoil my mood, and that would remain with me for whole day. I would never ask my husband to do anything, except for my son. He used to bring me vegetables once a week. He would bring vegetables for his mother too, who runs a tiffin shop in the morning time and prepared Idli and dosa. So, my husband used to have his breakfast there only. He also has diabetes. So, I used to concentrate on preparing vegetables, he used to have it but he would say that it doesn't taste like his mother's preparation. But my son used to take all item whichever I prepare to the college also, he never had any complaint about my food. But he wanted all roots and tubers, which doctors are telling me not to eat. But he used to buy more of it. What to do, for his sake I need to prepare it, today also I prepared that only.”(Mrs. M, Veerapuram, 20.10.2016).

There are many male members who struggle to have food on time. Some could afford for it but their nature of work would not allow them to have food.

31-year-old Mr. V(group I), who had diabetic for a said told that he used to work in canteen of an IT company and he used to make dosa, sambar and vegetables. He could not eat on time as he supposed to cook during the meal time at the office. He would manage with a cup of tea to suppress his hunger during meal time. He used to start from home early in the morning, so he would rest for some time in the noon, which actually reduced his food consumption.

Similarly, he would reach home late in the night. He used to have left over food if available in the canteen only, otherwise he had to travel for one and half hour to have food at home.

Another example is of Mr. S (Group I), 42 year old lorry driver, who struggled to have food on time. He said that if he would travel in the same route, as he did earlier, he would have located some restaurant along the way. So, he would calculate the time taken to reach that place around that time and have food there. If he could not find any restaurant on the way, he had to tolerate his hunger till he could locate one. Sometimes with the help of his cleaner, he would try to cook. But that was risky as they would need to keep all the items for cooking and halt the lorry for some time. What was worse was that on the highways, they would mostly get 'maida parotta' and spicy side dishes, which were not good for his health. So he finds everyday-coping with diabetes a challenging task.

Availability of food cereals and Millets – 'Rice' is for rich and 'Ragi' is for poor

It was observed that most of the participants of the study tended to attribute their diabetes condition (normal/abnormal) to their everyday food habits. They showed interest in the same and also asked their healthcare providers about the kind of food that would regulate their sugar levels.

It was also observed that people associated changes in their health to changes in food, crop cultivation patterns, methods of cultivation and especially, the use of fertilizers and pesticides. Earlier, two or three decades ago, people would go to the forests to collect the leaves which were used as fertilizers and so there were no chemicals in crop cultivation.

The use of rice was found to be more than the use of other food grains / millets. For example, 'raagi' was the one alternative to rice that people were consuming earlier. It was also mentioned by few others that they never took raagi, and rice was the only cereal they consumed a lot during their life time. Raagi is healthy but it is considered inferior to rice whereas rice is seen as more modern and superior. Ragi was viewed as food for poor and rice was considered as food for rich. One *mudaliar* woman pointed out that earlier they would give 'koolu' made of raagi to the people (most SC / ST) working in their agricultural fields, so they used to cultivate and keep raagi for their own use but nowadays the workers ask them to serve 'kanchi' made of rice. She stated people saw the serving of raagi as a kind of discrimination: "*They say that you people are eating rice and you are serving us raagi...serve us rice too*" (Wife of Mr. T, Ammanampakkam, 26.10.2016)

5.13. Caste, Class and gender dynamics in Ragi consumption

“Earlier we used to work in their agricultural fields/houses (Mudaliars) and we used to get ‘koolu’ (raagi malt), not ‘kanchi’(rice boiled in water). Sometimes, when my mother used to work there she used to get extra koolu, which she used to feed us, but nowadays everyone cooks nicely and eat. We also earn money out of work and which is enough to eat good food. But now I feel I am not in a position to eat well as the doctor advised to cut rice and non-vegetarian food as much as possible”(Mr. E, Suradimangalam, 25.11.2016)

He also added:

“They (Mudaliars) used to pour ‘koolu’ in our hands, they treated us like slaves, but now we are not going to their house for work or food, if we happen to go and work in the land, we take our own food or ask for extra wage (Rs.10) to have food, or would eat if they give us proper food (rice / sambar / karakolambu with vegetable).” (Mr. E, Suradimangalam, 25.11.2016).

Likewise, when the same question was asked in another village (Naickers), a participant said, *“We used to take ‘koolu’ often for lunch whereas we used to eat rice during dinner... few days only we used to take rice two times as meals, nowadays our children never prefer to take raagi ‘koolu’... this habit is slowly going away amongst most of us... very few still have the habit of taking ragi ‘koolu’ and few prefer to take during summer.”* (Mr. V, Kunnavakkam, 22.10.2016)

One couple, who belonged to backward caste, stated that they used to buy raagi and consume it at least twice weekly in the form of roti or dosa with onions /drumstick leaves.

Only one of the participants (Mr. M, Irumbulicheri) informed that he used to cultivate it and use it during summer months (mainly ‘Aadi’). He added, *“Whoever consumes ‘raagi koolu’ during summer would feel better and it would reduce the body heat”* (06.10.2016). Another important fact is that people used to serve ‘koolu’ during ‘Aadi’ festival, which is celebrated to worship the deity, ‘Amman’. People believed that if they kept her cool, she would not trouble her children with diseases like ‘chicken pox’.

Another participant, who used to cultivate raagi earlier, gave a different dimension:

“Nowadays, both the cultivation and consumption of raagi has become less, and that is the reason why the price of raagi is also raised in the market. I think people do not like it

because of it's colour. Nowadays people started moving out of the village for work, watching TV, exposed to several things. Again people are seeing many varieties in rice. If you go for a wedding, there you could see variety of items using rice only. Hence, people started liking variety rices like tomato rice, lemon rice, vegetable rice, karuvepila (curry leaf) rice, pudina rice, malli (coriander) rice and nowadays biriyani. The preparation of those rice varieties takes little time whereas 'raagi koolu' will require lot of time (preparation given elsewhere by Mrs. L). You know, people who used to go for company jobs can easily carry packed rice. Can we carry koolu like that??' (Mr. S, Veerapuram, 12.12.2015).

5.14. Habit of fasting and skipping medicines

Mrs. AD (Group II) and Mrs. UM (Group II) both shared that they used to observe fasting once a week and on some other auspicious days. They would finish their fasting only in the evening, when they would prefer not to take medicines as they thought they would reduce the blood sugar further. Mrs. UM said that she used to have only milk and biscuit first. If she felt hungry, she would eat proper meals, otherwise she would fall asleep. Whereas Mrs. AD used to fast for half a day, then she would take food and during dinner she would take medicines. Mrs. UM said that she would experience shivering (probably because of low sugar), so once she completed her prayers, she would take sugar or chocolate immediately.

The study by Neil and Drummond (1990) has shown that the participants could identify the hypoglycaemic condition easily because of the visible symptoms like shivering, sweating, dizziness, which were congruent with the medical understanding of diabetes.

Mrs. L (Group I) stated how food would be distributed among family members and how she would be left without food due to insufficient food and she would observe fasting.

"We never knew how much the men would eat, sometimes they ate more than usual. Same with children, so there would be insufficient food or no food me sometimes. Then I used to observe fasting but nowadays due to this sugar, I cannot tolerate my hunger, hence I try to have some tea decoction or rest for some time."(Mrs. L, Pandur, 08.10.2015).

It was observed that the food preference, purchase and distribution have much influence on the patients' eating pattern and schedule of eating. It was also observed that male dominance permeates in every sphere of women's lives. There was a struggle between the acceptance and resistance of such power played over them. There is also a subtle confrontation or suppression emotions visible in their expressions of everyday life.

5.15. Monitoring of diabetes - Visits to Hospital

Majority of the participants from Group I and Group II used to visit the government health facility or RUWSEC (NGO) clinic. Very few from Group II would visit the private health facility for treating their condition. Few others (Mrs. AD) would visit private hospitals to have other specialty tests such as renal function test or lipid profile.

Almost more than half of the participants (Group III) used to visit private health facilities including specialty hospitals. Among Group IV and Group V, most visited government health facilities, especially in case of female participants.

For instance, Mrs. M said that her husband and her mother-in-law both are diabetic. She expressed:

“I also have some expectations and need moral support. He would ask his mother whether she had food on time, medicines on time and also remind her to take medicines. He would get her medicines from the medical shop. But he would never ask me whether I had food or medicine. But they would expect me to take care of them in all the aspects. When I used to go to the hospital, I would inform him for the sake, because he is the head of the family. I should not leave that space for others to point my mistake”(Mrs. M, Veerapuram, 20.10.2016).

She added that she had to return home on time, otherwise her husband would call her several times as he expected that the women of a family should be at home before sunset. Sometimes, he used to take her to the doctor but he would not take her anywhere else. Lastly, she said, *“I feel relaxed when I visit my sister in my parent’s place. I had never shared my worries with anyone here, I would keep all my worries with me only”* (Mrs. M, Veerapuram, 20.10.2016).

Whereas Mrs. VK(Group I) said that she had to take care of her husband as he is the main breadwinner of the family. She used to visit the government health facility or RUWSEC, where she collected medicines at a subsidised cost of Rs.96 per month. Her husband used to visit a private clinic for his diabetes and he would spend around Rs. 500 for his medicines. She also justified his visit to the private practitioner that his diabetes duration is more (ten years) than hers (three years).

Similarly, Mrs. K (Group III) said:

“He would accompany me while going to the hospital... but he will not take care... Once, it was 2pm when we were done with all the tests. Later, when we were waiting to see the doctor, I asked him to bring some food as I was hungry... He brought me two idlis from the nearby shop and you know the condition of the idlis... sambarsmelled like it was spoiled...But he went and had food in-between... if he had that love and concern for me... he would have brought me whatever he had for lunch... but he always would point out the expenses... had spent this much for this... this much for that... Sometimes, I used to cry alone.” (Mrs. K, Pattaraikazhani, 13.10.2015 and 29.12.2016)

She further added that her husband wanted to show that he looked after her well but that never translated into action.

In contrast, Mrs. UM shared that her husband would always check that whether she had food and medicines on time.

Mrs. MU (Group I), who was recently admitted to a hospital for cardiac problems, was looked after by her niece at home until she recovered from the condition. She was given a balanced and healthy diet as her niece had a degree in nursing education. She mentioned that she was also experiencing asthma and it added on bodily discomforts and symptoms like breathlessness. Hence, her recovery took longer than usual. After a week, she started performing daily activities slowly and her niece left her household. She then had to take help from another niece in the village to inject insulin. Her husband accompanied her for the hospital visits and helped her in fetching water and performing other household chores. Later, he left for his job outside the city where he worked as a lorry driver. Then, her son started helping her in fetching water and other difficult chores which she could not perform.

Mr. SA (group I), 55-year-old male, who is ill with multiple morbid conditions (diabetes, arthritis, cardiac problem, kidney problem, spondyloarthropathy, keratoderma, and hemmorrhagia) could not visit the doctor on his own. No one would take him to the hospital. In the past, his sons would get medicines on and off, but his wife only paid for them. She used to give money to buy medicines by selling vegetables.

Mr. SH (Group V), 71 years of age, was a retired teacher from back ward caste, who successfully restricted his diet, did regular exercises, and took medicines regularly. He got a cataract surgery done within a month of diagnosis of the cataract problem. Whereas Mr. T

(Group I), unemployed, 65-years-old, struggled to reduce his sugar in order to undergo cataract surgery even after several months of his diagnosis.

5.16. Dependent elder adults and coping with diabetes

Mrs. P, a 55-year-old widow belonging to backward caste Muslim, lived in a thatched (polythene) roof, and had been suffering from diabetes for more than five years. She said:

“I have to take food proper first. I have two sons, but what is the use? Both of them are living there in Kalpakkam (which is 15 kms away). Earlier, I used to get Old Age Pension (OAP) money (Rs.1,000), and I would work if I would get work in MNREGA. Now, I do not get that also as they left out my name. I need to eat, know. Every day, I try to get some milk and biscuits for morning breakfast or sometimes I get 4 idlis from the shop which cost Rs. 12 or I buy little rava and wheat flour... prepare dosa in the night... I used to go to Tirukalukundram Government Hospital for diabetes and spend from Old Age Pension (OAP) for other sickness like fever and other problems. I would spend Rs.150 at the doctor’s, then additional one Rs.150 if the tests were prescribed. If I need to collect test reports the next day, I have to spend extra Rs.40 - Rs.20 for travel and Rs.20 for tea and snacks. I could not spend on food in the town and I would prefer to buy tea and vada if I would feel hungry. But now they stopped giving me OAP. Now, my sons are also not helping me... not giving ration rice too, I am getting it from my neighbour, you know. She shows me sympathy and gives me 4 or 5 kg every month. I used to manage with that. My daughter is here only living in the same village but her condition is also not good, alcoholic husband, he behaves violently. Hence, I am not going there too. (Mrs. P, Kamaraj Nagar, 24.12.2015)

She experienced vision problem for several months. Somehow, she tried to get it tested for free in a Medical College Hospital through a camp. She was advised to use spectacles for vision problem. She informed both of her sons but they did not bother with it. Later she tried to take loan from the money lender to start a small business for selling snacks in the village itself. Her second son came to know about it and he took that money from her and did not return that money. She said that this created a lot of problems and she could not find any other ways to pay back the money. She added:

“My neighbour is the only person who bothers if I am not seen around, nobody else shows concern. She used to refer me to work like doing household chores, assisting in

cooking for any events which take place in and around the village.” (Mrs. P, Kamaraj Nagar, 24.12.2015)

Mrs. PB, a 65-year-old widow from most backward caste, had been living with diabetes for more than 10 years and was having vision problem for several months due to cataract. Few months earlier, when she started experiencing blurred vision, she visited the doctor, who advised her to go for cataract surgery. Due to diminishing eyesight, she started curtailing her activities. She also started experiencing breathlessness sometimes. Her routine activities were also reduced. Earlier, she used to help in household chores. She was not taken for the eye surgery either by son or daughter-in-law. Her physical mobility became less due to vision problem and she stopped going to the hospital to get medicines for diabetes and heart disease. She requested one of her relatives who used to go treatment to CMCH to get her medicines as she could not travel alone because of her vision problem. Her conversation with her neighbours also decreased.

The relative who used to visit to CMCH for his diabetic condition used to buy Mrs. PB’s medicines too by requesting the staff there. When the doctor advised her to undergo cataract surgery, she had to wait for her daughter to take her to hospital for the procedure. She was living in a small room in the corner of the house. Her grandchildren used to give her food in a plate in the morning. Sometimes her daughter-in-law used to serve her lunch in the afternoon, sometimes she would not. One day when I visited her, her plate was kept next to her with flies sitting on the food. She had fever, but nobody was around. When others (neighbours and relatives) started visiting, her granddaughter came with a coffee tumbler and a tablet. She was half-conscious, so one of her relatives tried to feed her the coffee and medicines. Then her daughter in-law said that she and her husband were busy in the agricultural job. She had to go for her anganwadi job, too. Her children had exams then, which was why they could not take her to the hospital. She also mentioned that one of her daughters, who would reach the next day, would look after the doctor’s visit.

Across classes, the elderly who are dependants experience challenges in fulfilling the everyday needs of diabetes. Majority of the dependent elderly faced challenges in having three meals a day. One of the participants said that it was difficult enough to get three meals therefore it is almost impossible to follow the doctor’s advice to have several small meals. In many houses where the food was prepared by daughters-in-law only, the elder female patients

were often involved in conflicts in terms of preparation and distribution of food, leading to misunderstandings and quarrels.

Everyday coping is very different in case of Mr. SN (group II), a 73-year-old belonging to most backward caste. He had fallen sick since he was diagnosed with cerebro-vascular disease. His wife, who was 65-years -old, was the only person who used to take care of him. His daughters and sons got married and settled in different places. They used to visit him only when he fell sick. His wife used to feed him medicines regularly. But after he fell sick, his food consumption got reduced. So, he experienced fluctuations in his blood sugar and would faint sometimes and had to be taken to the hospital. He started forgetting things. He was at home alone when his wife would go for MNREGA work or any agricultural labour. She was not supported by her children in caring for him. They used to give her few hundred rupees during their visits. She was struggling to meet the daily expenses. He happened to faint few times in absence of his wife and his condition became severe. When she thought that she could not handle him alone, she informed her daughters. Then two of his daughters had stayed with him few days each. Meanwhile, he was hospitalised few times in the Medical College Hospital but could not save him.

This chapter on ‘everyday-coping with diabetes’ has shown the routine activities of the study participants, their everyday life in terms of work, food, sleep, illness, family dynamics in sharing and supporting the roles, caring and monitoring of diabetes, multiple layers and interactions across different spheres of life mainly the house and the work environment. The next chapter will deal with the ‘interactions of the individuals with health care services’.

This chapter has shown that how individuals in the poorer section struggle to find employment. For instance, Mrs. S, who would work when her entitled work was allotted under MNREGA. But later she would try to take up the same job instead of her relatives who actually would not work under MNREGA and for which she had to pay them a little amount as a commission. As the Panchayat clerk knew about her family condition, that her husband could not go for a job and take care of his visually challenged and mentally retarded elder son, he let her to do work instead of others.

Several men in the class I were involved in informal jobs such as working in a petrol pumps, cooking in a canteen, driving lorries, cleaning exhaust lines at atomic power station, Kalpakkam, and so on. It was also learned from one of the male participants that the contract

jobs at Kalpakkam would be provided not directly through the authority of atomic power station but through some middle men and contractors who actually used to hire people. They also took a 'cut' out of their payment every month. It is important to note that Mr. M who also suffered from TB was one such contract employees who involved in cleaning exhaust line at Kalpakkam. Exhaust cleaning job might be a reason for onset of his TB. Because of his ill-health due to TB and diabetes, he could not go for a job again. Mrs. M's case was an example of how health consequences of diabetes (hypoglycaemic condition) became a reason forcing her out of her job. Few women in the working class could not work because of other complication such as foot ulcer. Women belonging to the Muslim community, who were involved in rolling beedi is, left the work because of diabetes and consequently lost the income out of it. It can be interpreted that employment and health are both equally important as employment affects socio-economic condition of the individual, which further influences the management of diabetes. Diabetes also affects the work productivity of the individuals affected.

Mrs. S's case shows that a kind of support system was, however, established when she could not find her job and started working on behalf of her relatives who were not working under MNREGA. But whether the income was sufficient or not was again a question mark. Especially as it was also observed that the individuals in group I consumed very less vegetables and pulses whereas it was plenty among group III and group V.

Class II, (who were involved in farming as well as work under MNREGA) can be viewed as a group mainly of women who struggled more in terms of physical/mental stress. For instance, Mrs. M, Mrs. AL, and Mrs. UM who used to work under MNREGA, also used to care of the cows and work in the agricultural field when required. In contrast, men in the family would work only in the agricultural field and milk collection from cows in addition. Cows were fed with fodder/rice/paddy husk and water by women when they were tied in their shelters (at home). Collection of cow dung and cleaning of the shelters was done by women in common. Very few men were involved in these activities. The women belonging to marginal farmers across caste group shows similar work patterns.

5.17. Conclusion

This chapter has also shown that how participants who were landless labourers, widows, and dependent elder adults struggled to satisfy their hunger. For instance, Mrs. S mentioned that she would buy rice (distributed in PDS) for money (Rs.10) from others when the rice which

she collected from PDS would get over. Whereas women belonging to marginal farmers and little higher classes mentioned that they would PDS rice only for Idli/dosa because the cooked PDS rice would not be good for consumption. It was observed that few others in the farming group mentioned that they would use the PDS rice to feed their cows. Whereas elder dependant, Mrs. P, had mentioned that her neighbour would provide few kilos of PDS rice free of cost because she did not have the ration card.

Men, who were working outside the village, travelled long hours for work, and could not manage their routine, food timing and compromised with the quality of food. For instance, Mr. V, who used to work in the canteen of a software company, had to start early from home to leave for work and also returned from work very late at night. He had to eat there in the canteen but after meal time was over as he needed to prepare food during all the meal timings. But in case of Mr. P, who used to work for long hours (two days and two nights) was given two hours each to have lunch and dinner at home, and he was allowed to sleep for some time during night, when someone else would take care of his driving work. This helped him to take good care of his diabetes condition and also allowed him to perform few activities at home. He mentioned that a major constraint because of his work routine was that it never allowed him to do any physical activity as per the doctor's advice i.e. walking or exercise.

It was also observed that there was a gender difference across class in treating diabetes in terms of type of health facility, blood test, food timing, type of food and food distribution. For instance, Mrs. M mentioned that she used to prepare vegetables, which are good for sugar patients, mainly for her husband. Mrs. K said that her husband was the main bread winner of the family, so he needed to be cared for properly. So, while he must visit a private health practitioner for his diabetes treatment and get regular blood test, her treatment at the government health facility was sufficient since the duration of her diabetes was lesser than that of her husband's.

CHAPTER 6

Individual's Interaction with Health Care Services for the Treatment of Diabetes

6.1 Availability and Accessibility of Type of Health Facility for initiating and continuing treatment for diabetes

6.1.1. Health facilities accessed by the participants for treatment of diabetes

There are several health facilities accessed by the study participants as given in the above figure (6.1.1)²⁸. The participants accessed several sources for diabetes ranging from primary health centre, private clinics to the super specialty hospitals of the tertiary health facility of both public and private health facilities. There are also Private (non-profit) clinics accessed by the participants. Similarly, they accessed different systems of medicines ranging from Allopathy, Siddha, homeopathy and Accu- Healing.

Firstly, the attempt is made to study the availability of primary level providers at both public and private health care services which provides the diabetes care in the given context. This study mainly focused on the interaction between the patients and the primary level of health care providers. In order to understand the interaction between the patients and health care providers, it is also important to study the type of health facility, its structure and function, experiences of patients in accessing care for diabetes, responsiveness of the health care services. It also includes the understanding and treating diabetes patients from provider's perspective and importantly the facilitating or constraining factors in the provision of diabetes care.

The three important public health facilities which were accessed by the participants include:

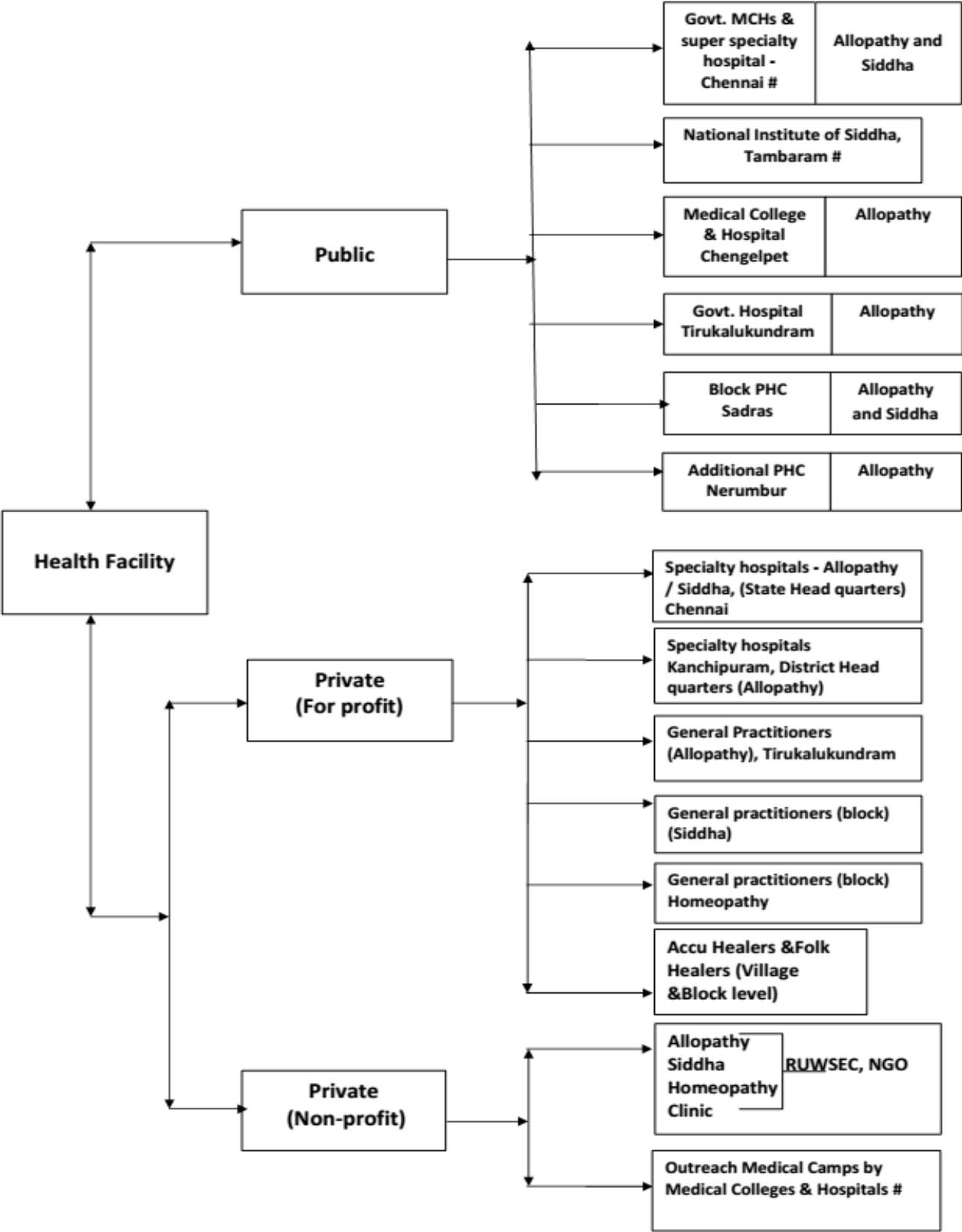
- a. Primary Health Centre, Nerumbur
- b. Government Hospital, Tirukalukundram
- c. Chengalpet Medical College, Chengalpet

The private clinics/hospitals at Tirukalukundram and private specialty hospitals at Chengalpet were accessed by the participants. Few other public and private tertiary health facilities at Tambaram and Chennai (state headquarters) were also accessed.

The primary health facilities for the study include not only the public health facility but also the private clinics run by the general practitioners located in the main town of the block i.e. Tirukalukundram and also Private (non-profit) clinics run by NGO. Here the only private (non-profit) clinic run by RUWSEC (NGO) was taken for the study purpose.

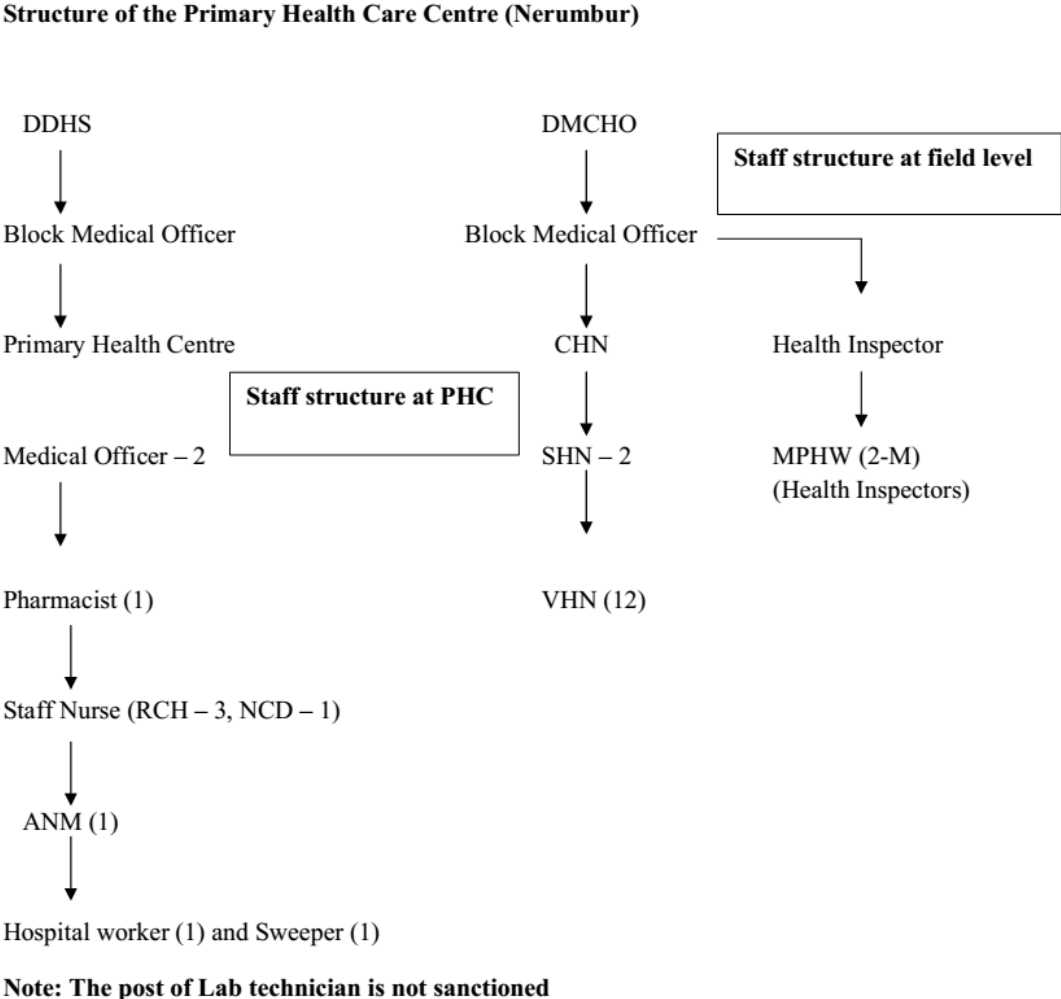
²⁸This figure is drawn after mapping the health facility accessed by the study participants who took part in the first phase survey

Figure 6.1: Health facilities accessed by the individuals affected with diabetes



6.2. Structure and functioning of the primary health care services in the provision of diabetes care in the given context

Figure 6.2.



6.2.1 Functioning of the Primary Health Services in the provision of diabetes care

6.2.1. a. Government Health Facilities

The government Additional Primary Health Centre (PHC), Nerumbur which serves around 40,000 population and Block Primary Health centre, Sadras serves around 1 lakh population.

The main government primary health facility which is closest to the study villages is the additional primary health centre at Nerumbur. Hence the focus was given to study the health care providers at the additional primary health care facility. Few health care providers especially the doctors and staff of the NCD clinic were also included from the block primary

health centre. This was in order to understand the activities related to diabetes prevention and control and functioning of the NCD clinic. The block PHC which is located at Sadras serves around 1 lakh population. Among two doctors posted at the primary health facility (Nerumbur), one doctor would be posted most of the time in the block health facility (Sadras) based on the need.

As per the standard guideline, two Medical Officers have been sanctioned for the Primary Health Centre, Nerumbur. Based on our interviews we learned that two medical officers are posted as per the sanctioned number. However, one medical officer is on diversion to the block level PHC as there is larger patient load. It is also noted that three staff Nurses (RCH - 2, NCD-1) are posted against four staff nurses sanctioned (RCH - 3 and NCD -1).

There is no post of a Lab Technician sanctioned since the establishment of this Primary Health Centre at Nerumbur. There are two Lab Technicians visiting this PHC on Tuesdays and Fridays from other Government Health centres. On Tuesdays, all the ANC mothers visit the centre and GCT is done for them and other fever cases are also tested. Friday is meant for people with diabetes.

About NCD Clinic at the Government Health Care Facilities

In addition to maternal and child health, family welfare and other disease control programmes, NCD clinic is also in place to provide services for prevention and control of Non-Communicable Diseases such as Diabetes, Hypertension, Cancer (mainly women for cervical cancer) and Cardiovascular Diseases. The NCD Clinic is located in one corner of the PHCs and CHCs. This NCD corner is handled by the staff Nurse, who is trained in screening the persons for diabetes, hypertension and cancer (cervical cancer). The opportunistic screening is done when the person above 30 years would visit the clinic. In the field, sub centre level health awareness programmes are conducted on diabetes, hypertension and cancer (Selvavinayagam, 2017).

If the person is diagnosed with diabetes, then the medical officer starts treating the patient with lifestyle modification or with oral hypoglycaemic agents. The patients with presence of complication or abnormal sugar (mainly hyperglycaemia) are referred immediately to the tertiary care centre at Chengalpet Medical College and Hospital (CMCH) for further management. A staff nurse is trained for the purpose of providing services related to NCD. The roles of staff nurse (NCD) includes

- 1) Filling the patient card which includes all demographic details, anthropometrics, food habits, habits of smoking/alcohol.
- 2) Blood investigation such as blood sugar / urine analysis – urea/creatinine / advise the patient to visit the PHC on a particular day for the blood tests (based on the days when the lab technicians will be available)
- 3) Health education through flip chart
- 4) When the biochemical profile is abnormal, the patient will be referred to the medical officer for further management (MO would prescribe medicines as per the standard protocol).
- 5) Documenting and updating the details of the patients in the HMIS.

Issuing medicines regularly to the known diabetes / hypertensive patients, monitoring of blood sugar three months once at regular intervals are also happening as part of the primary health services.

In case of complications, the patient will be referred to CMCH for further management (Selvavinayagam 2017, NPCDCS policy document; interviews conducted among the staff nurse at NCD corners at Primary Health Centres (both main / additional PHCs during April/May, 2017).

6.2.1.b. Private clinics run by the General practitioners

The health care providers, mainly doctors working in private clinics which were mostly accessed by the participants have been included in the study. There are four important clinics / hospitals located at Tirukalukundram considered for the study.

All the facilities have an attached pharmacy and laboratory facilities. ECG is available only in two health facilities. The people who have diabetes with complications are referred to the specialty centres at Chengalpet. Few Specialist doctors like Cardiologist used to consult in a hospital at Tirukalukundram for two days in a week and patients also visited them.

6.2.1.c. RUWSEC (NGO) clinic

RUWSEC runs a Sunday clinic for people with diabetes and hypertension. Around 30 to 40 patients with diabetes would visit the doctor on that day.

Apart from this, RUWSEC conducted awareness / education programmes in the villages. The volunteers as part of this diabetes project would visit Primary Health Centre and educate the patient on healthy life style, healthy food, regular intake of medicines, regular physical

activity, monitoring of blood sugar through regular blood tests minimum two months once. A separate patient counsellor is posted in RUWSEC who dealt with a range of patients with different kind of health issues such as reproductive health, diabetes, cancer and also mental health. If they could not handle any patient, for example, a patient with depression, they would refer that patient to other health care facilities/NGO which is an expert in dealing the patients with such problems.

The patients with complications are also referred by RUWSEC for further treatment at the specialty hospitals located in the state headquarters. They also have a good rapport with such specialty hospitals through which they get treated the poor patients in the villages. For instance, it is observed that they have a rapport with an Eye Care (Rajan) hospital in Chennai, used to conduct annual eye screening camp for these patients and also sent them there for further treatment like cataract surgery. They also conducted annual camps for the poor and needy patients to assess lipid profile and other important tests for diabetes patients like HbA1c and kidney function tests.

These are the available health facilities at the primary level which are focused for the in-depth study of the health care providers in order to understand the provision of diabetes care and also to study the interactions of patients with health care services in terms of accessing diabetes treatment.

Before understanding these interactions between the patient and the health care provider in detail, it is important to have an overall understanding of where and how the study sample accessed diabetes treatment.

6.3. Type of Health facility accessed by the study participants

It is observed that around 60% of the participants had accessed the private health care facilities to diagnose and initiate the treatment. There is no significant variation across gender in the type of health facility accessed for initiating treatment. It is important to note that there is a substantial shift from private to public health facilities for continuing treatment. There is considerable variation in accessing health facilities for continuing treatment. A total of 37.4% of the male participants were found to be continuing treatment in public health facilities compared to 44% of the female participants who were continuing in the public health facilities. In general, people visited private health care facilities for acute illnesses. This was the case even for other conditions when they resorted to the private clinics where they came to

know about the presence of chronic condition like diabetes. Given the prolonged treatment involved for diabetes the cost was a burden and hence they moved to a public health facility or other facilities where they could spend less for their treatment. The results also revealed that 35.6% of the male participants were getting treated at the private health facilities whereas only 16.5% of the female participants were taking treatment at the private health facilities. Similarly, a significant proportion of females (26.4%) were taking treatment at non-profit private clinics importantly RUWSEC’s clinic compared to the male participants (14.4%). It is found that 9% of the male participants and 2% of the female participants have had discontinued the treatment.

A small proportion of the participants also tried to take treatment from both public and private health facility or private and non-profit clinic or public and non-profit clinic. The details are presented in the Charts 6.1 and 6.2.

Chart 6.1.: Gender distribution of Type of Health facility accessed for initiating treatment

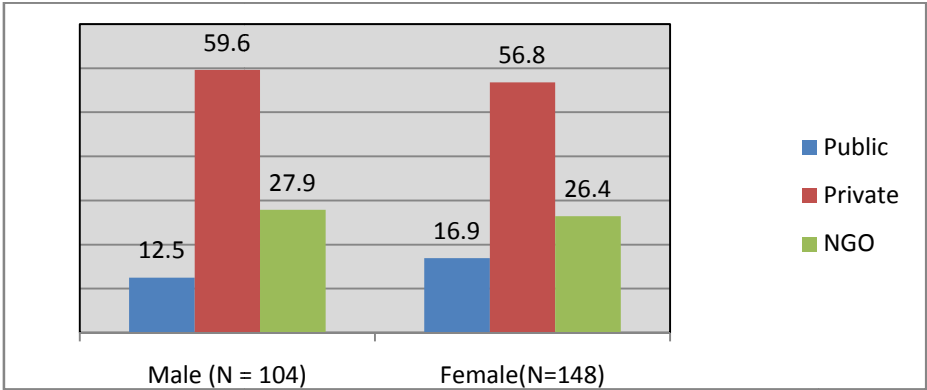
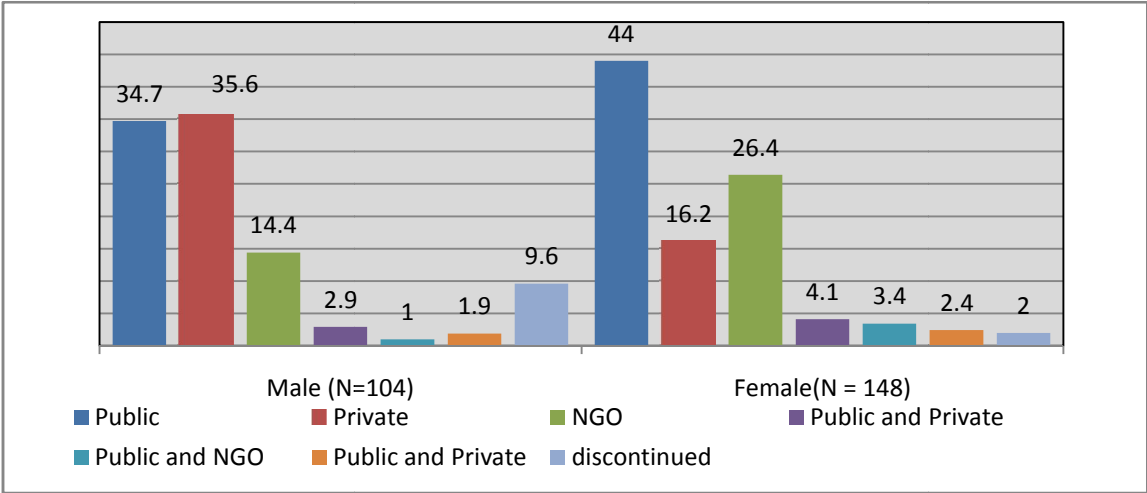


Chart 6.2: Gender distribution of type of Health facility accessed for continuing treatment



The caste wise information in initiating and continuing treatment at different health facilities has brought out a clear pattern. When we look across caste groups where did they initiated treatment, there was no significant difference across caste groups in accessing public health facility. More than 50% (see chart 6.3) had accessed private health facility and when we look into the chart (6.4) a clear pattern of access is visible as the proportion of patients accessing to private providers got reduced and there was a rise in accessing public health facility and clinic run by NGO.

Chart 6.3: Caste distribution of type of health facility accessed for initiating treatment

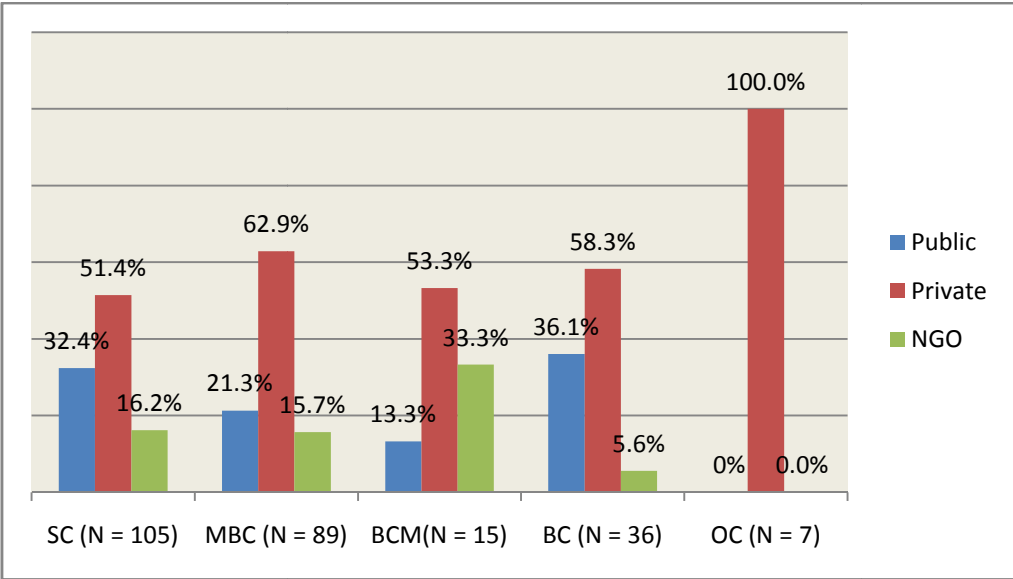
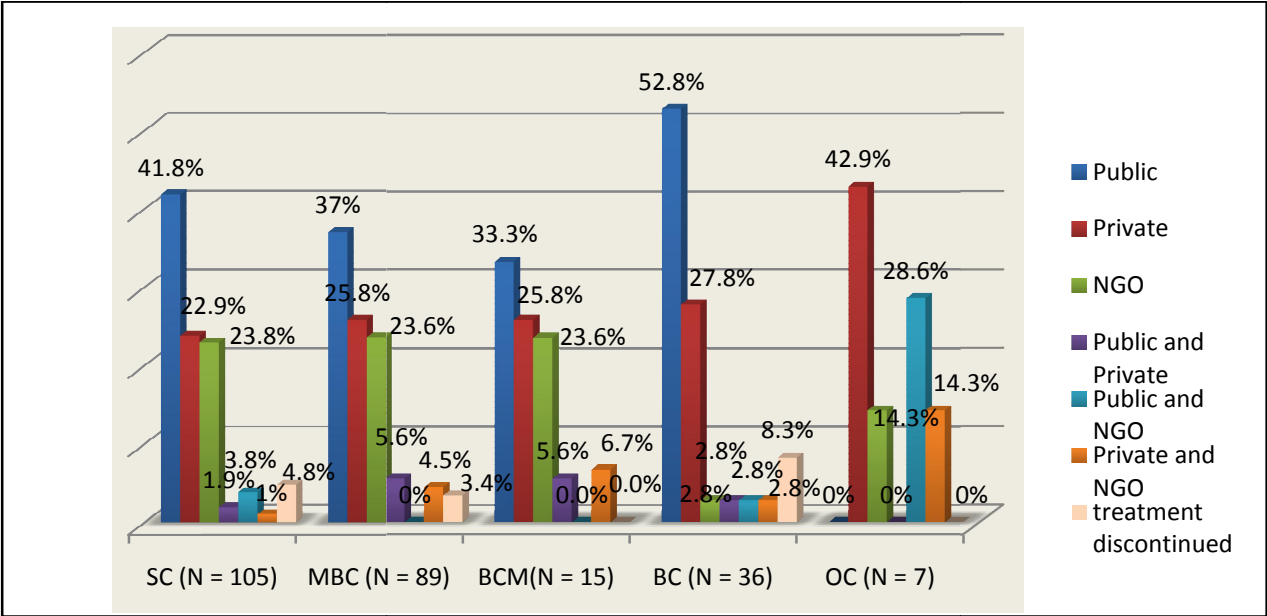


Chart 6.4: Caste distribution of type of health facility accessed for continuing treatment



Likewise, A similar pattern is observed across classes (refer figures 6.5 to 6.8) There are two figures a and b, which corresponds to initiating and continuing treatment. The class wise information has given much clearer pattern. Firstly, it is noted that the proportion of participants of each class has shown a difference in accessing health care facilities. It is significant to note the shift from private to public and non-profit health facility. The proportion of landless labourers who accessed the public health facilities is high (44.6%) compared to other groups, the marginal farmers (29.3%), the small and middle peasants (16.7%) and the government job holders/retired/professionals (42.9%).

Figure 6.5: Class (Landless Labourers N=137) distribution of type of health facility accessed for treatment

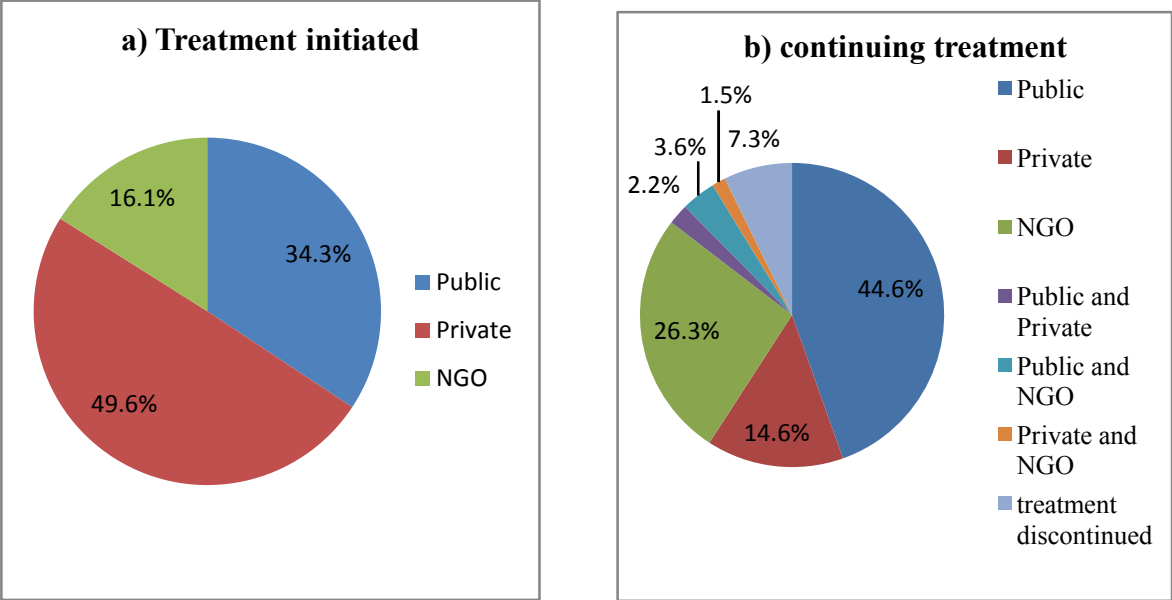


Figure 6.6: Class (Marginal Farmers N=41) distribution of type of health facility accessed for treatment

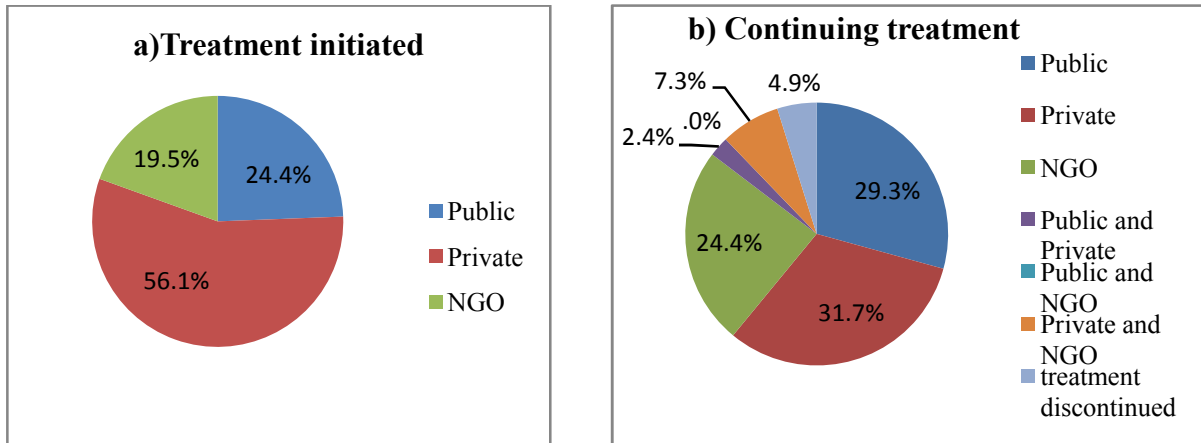


Figure 6.7: Class (Small and middle Peasants N=18) distribution of type of health facility accessed for treatment

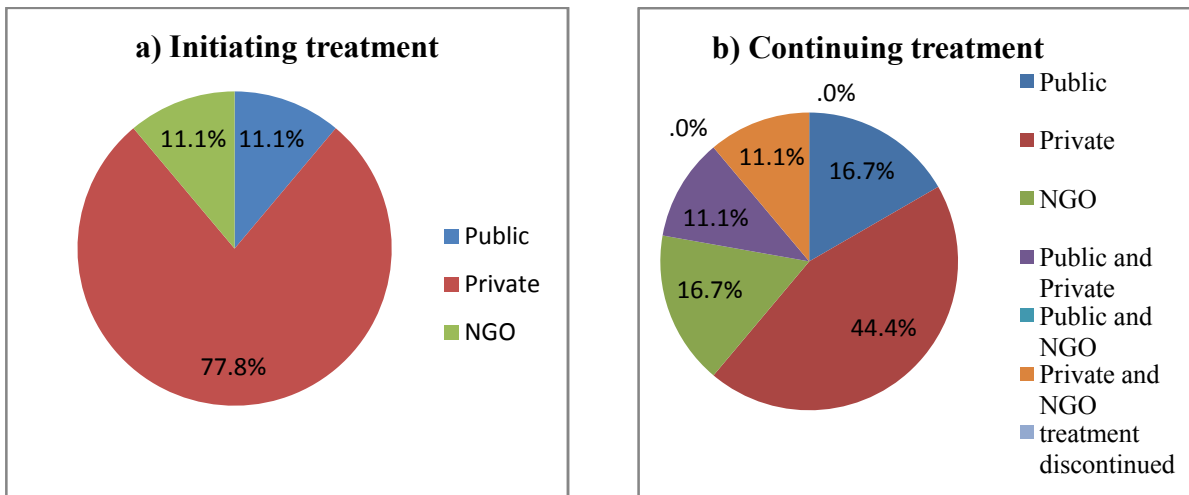
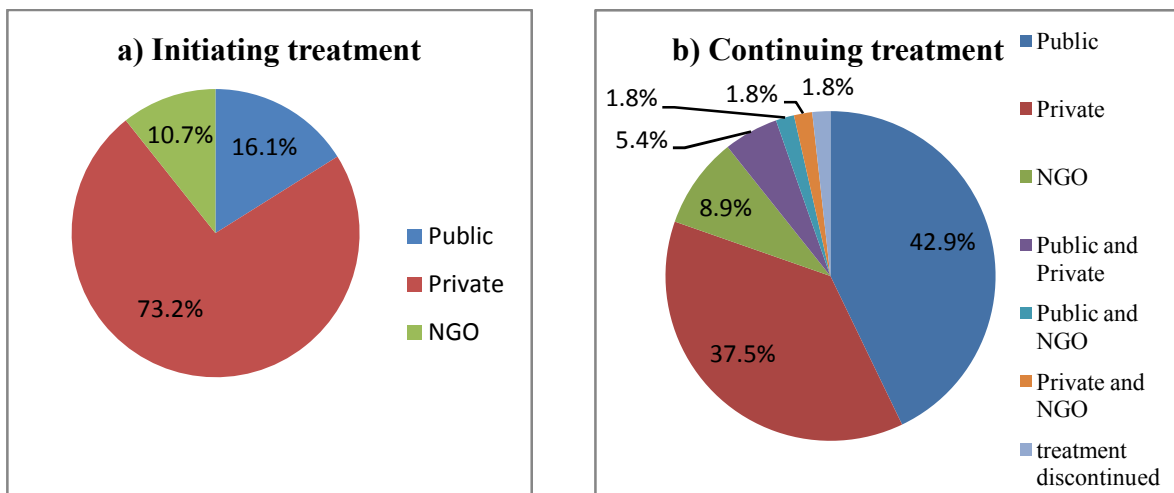


Figure 6.8: Class (Government Job/ Retired/ Professionals) distribution of type of health facility accessed for treatment



6.4. Plurality in Treatment Seeking (Parallel Healing / shifting from one system to another)

Around 18% of the study participants accessed different systems of medicine such as Homeopathy, Siddha, Accu Touch other than Allopathy, either as a mono therapy or in combination. The use of home remedies/ herbal remedies was seen among 7.6% of the study participants, of which, 3.2% were taking only home/herbal remedies and the remaining 4.4% were taking home /herbal remedy along with Allopathy. This is represented in Table 6.1. They used to take those remedies without any professional advice. Often it was information that they received from neighbours or extended family. Powder from seed of “Naval Palam” *Syzygiumcumini*, known as **jambul**, jambolan, jamblang or **jamun**, Insulin leaf(*costusigneus*) - Neyccarikamaram or Venkai-c-ciray or Kostam in *tamil*, Aavaaram poo(*Senna Auriculata*), fenugreek powder, bitter gourd juice, aloe vera juice, concoction of Guava leaves and several other herbal products in the market such as “diaba care”. Then Siddha medicine was found to be the next most popular medicine that was used by 5.2% participants. A small proportion of them took Accu healing (2.4%), an even smaller proportion Homeopathy (0.8%) and folk medicine (0.8%) respectively. The common use of remedies like fenugreek was found when people had experienced some acute illnesses like stomach pain and very few (0.8%) had approached folk healers and spiritual healers to heal their illness.

Table 6.1: Different systems of medicines accessed by the study participants (phase I)

Systems of medicine	Number of respondents (%)
Allopathy	207 (82.1)
Allopathy& Siddha	8 (3.2)
Siddha	5 (2)
Homeopathy	2 (0.8)
Allopathy& Homeopathy	1(0.4)
Herbal/home remedy	8 (3.2)
Allopathy/herbal/home remedy	11(4.4)
Allopathy &spiritual healing	2(0.8)
Folk medicine	2(0.8)
Allopathy/ herbal/Accu healing	2(0.8)
Accu Healing	2(0.8)
Allopathy &Accu Healing	2(0.8)
Total	252 (100)

Source: Field Survey, 2015-2017

The gender wise utilization had shown that 22.4% of the male participants and 14.2% of the female participants sought treatment from other systems of medicines. The caste categories had shown that 14.3% SCs, 14.3% MBCs, 6% BCMs, 36.1% BCs and 14.3% OCs were taking medication from other systems of medicines. Similarly, the class wise categories had shown that 12.4% of the landless labourers, 18.6% of the marginal farmers and 26.8% of the participants who were employed in the organised sector. The gender variation was not statistically significant whereas caste and class wise utilization pattern of Allopathy and other systems of medicines were showing a significant difference at $p < 0.05$.

6.5. Treatment seeking for better care or cure

Majority of the participants who took medication from other systems did so after getting advice from relatives, neighbour, friends and other social networks. They used to either continue or discontinue the medication based on the levels of satisfaction. For instance, there are patients, mostly female, who experienced more of foot ulcers. They tended to take medicines from other systems of medicine. For instance, Mrs. S, a 56-year-old female from Ammanampakkam village said that she consumed a siddha product for 48 days that her son, on recommendation from his friends, had ordered it from Palani, which is around 400kms away. She got diabetes when she was 50 years and developed this foot ulcer 4 years later. She had to get her toe amputated a year ago. Her son brought her this herbal product as her sugar was not reduced. But even after consuming that product she developed a foot ulcer again and hence she resorted to Allopathic treatment.

Another participant Mrs. R, 38 years old, diabetic said that she had it for four years. She was scared that she might get kidney problems because of sugar. This was because her father had kidney problems due to uncontrolled sugar. Hence, she tried to combine some herbal remedies along with Allopathy medicine. As she mentioned,

“I used to take these drumstick leaves or guava leaves minimum once in a week. People used to tell that this would reduce sugar in the blood. After I heard from my neighbours, I started taking concoction of guava leaves. I also heard once from a siddha practitioner that guava leaves would help in reducing the sugar” (Mrs. R, Nerumbur, 06.06.2016)

She also mentioned that she could not walk because of her disability. Pointing to her leg, she said that her feet had bent when she was in 10th standard as a result of which she used to

have discomfort and stiffness while walking a long distance. She sought treatment from RUWSEC and the doctor advised her to take calcium tablets. She used to take treatment for diabetes from the PHC and collected her medicines from there. But she preferred to do lab tests at RUWSEC and also take calcium tablets.

From Mrs. R's treatment seeking behaviour it can be said that she uses both private and public health facility for her diabetes and other ortho-problems. She also experiences anxiety towards onset of complications because of uncontrolled diabetes and hence she is also trying to use other herbal remedies.

Few others had started taking herbal remedies like guava leaves and left it after they started experiencing some other problems

"I used to take guava leaves, but it was heat for me and I left it then. Now I am taking only allopathy medicines" (Mrs. AL, Karumarapakkam, 25.03.2016)

My son used to prepare some herbal remedies and he would give me also. He would use this nithyakalyani poo, avarampoo, one day one thing. I used to take insulin. So, I would take that also to reduce my sugar which would be remaining the same even after taking insulin regularly" (Mrs. S, Mettu Egai, 08.03.2016)

My foot ulcer has not healed since a long time, may be six months. My brother who visited me few months back brought me this 'aloe vera juice' and he said that will definitely reduce the sugar. Now I consume it every day. (Mrs. AM, Nerumbur, 29.12.2015)

Whereas Mrs. V, 45 years, diagnosed with diabetes seven years ago also suffered from unhealed diabetic foot for more than 3 years now had stopped going to any health facility and discontinued medicines from Allopathy after visiting several health facilities from private clinic to private specialty hospitals. Since then she started taking bitter gourd juice weekly twice. She said that

"I had spent around 6000 rupees, but what is the use, all they did was dressing my wound. You know I experienced a lot of pain, once it was little swollen, I could not keep my feet down, then I removed that dressing and pressed my wound a little, full of worms, then pus, then blood, then I decided I would never go to the hospital anymore for treatment. I used to apply only turmeric powder. I used to keep my feet in water and all, but I used my foot wear when I would work in the mud when I used to water the plants" (Karumarapakkam, 25.03.2016).

From the above-mentioned treatment experiences of the participants have shown that how individual's decision of treatment is not only based on perception /understanding of illness

but also the interrelationship situation of other individuals' relatives or friends or neighbours or any other social networks. Hence the decision making in treatment seeking is a rigorous, intra-individual and inter-dependent.

In addition, it shows that there are number of factors which influence the plurality treatment such as high treatment cost, non-availability of resources such as human resources, equipment at the health facility, timing of the health provision, and so on. There are other important reasons like the relationship between the patient and the healthcare provider which can also be considered as an important determinant in treatment seeking behaviour.

6.6. Community Network in treatment of diabetes – case of Accu Healing in Ammanapakkam Village

A group of ten people from the same village used to visit the Accu healer once in fifteen days. Majority of them were people with diabetes. One of the participants, 66 year old Mrs. E, visited this Accu healer with a referral from one of her relatives. She lived with diabetes for 21 years and developed co-morbidities such as thyroid, blood pressure meanwhile and later triple vessel disease. She tried out several specialty hospitals to treat the condition and the doctors advised her to undergo a surgery after performing an angiogram. But she was not willing to undergo surgery. Her sons were also willing to spend for treatment. One of her sons who is a software professional abroad had the means to pay for it. Another son who settled in the state's headquarters informed her that he would take care of her entirely. She was not convinced as she was scared that she might happen to die during the surgery. So, she wanted to live as long as possible without any surgery. She also thought that the amount which they would spend for treatment might go waste if she would die during the surgery. Hence, she wanted to take treatment from other systems of medicines and did so.

During the initial period of her treatment she was happy as she did not have to face any dietary restrictions. The Accu Healer advised her not to take only few items such as milk, chicken, fruits like 'chikoo'. She was asked to consume more fruits including grapes, banana, orange, apple etc, during morning without having coffee or tea. Later she used to have breakfast. She used most of millets flour for making 'dosa'. Before visiting the accu healer she used to go for a walk up to her agricultural fields from her house in the evening. The distance would be around 1 km. After she started this process of Accu healing she stopped walking also. She was advised not to reveal any of her bodily discomforts to any one so that she continued to have a feeling that she was alright. But she would experience loose motions several times in a day. The healer would tell her that the toxic substances, which were

stagnant in her body were being excreted and that she would be better after a few days. The healing would take place when the patient would have faith in the healer's words. She said that sometimes she would feel better but other times she was having loose motion for the whole day. But she did not return to Allopathy and also did not go for any blood test as advised by the Accu healer. After two years, she experienced foot ulcer and which was not healing and when her blood sugar was much higher around 460mg/dl. Similarly, the faith dynamics could be observed among other patients too.

On the other hand, Mr. T, 74 years, old and diabetic for 15 years said that he had to take Allopathy medicines for his sugar and this Accu healing was good for his asthma problem. He also used to take some herbal remedies to control his blood sugar. Similarly, Mr. U, 54 years, had diabetes for 7 years also visited the Accu Healer was not convinced with Accu Healer's advice mainly on not monitoring the blood sugar. As he was keen on checking the blood sugar, he checked his blood sugar and came to know that his blood sugar was in the same level as earlier. He continued with his Allopathic medicines but he would visit the Accu Healer on and off. Both Mr. T and Mr. U had never revealed to the Accu Healer that they were continuing the Allopathy medicines and they had a check on the blood sugar level.

The interview with the Accu Healer also revealed that the healing or cure of any condition depends on the build up of toxic substances which had to be excreted from their body. He added that the chemical effect of the Allopathy medicine also added to the toxicity. There are patients who would recover sooner. He shared that his own experience of illness which he got cured from 'Accu Touch' and 'Varmam' and then he got interested in learning the therapy from the healer who treated him and took training under other professional healers.

He also conveyed that the faith of the patient only would do half the healing process and the patient need to believe that he/ she is well. He said that he would build the confidence of the patient first and then inform them that they supposed to follow the treatment with number of sittings and that depended on the nature of the condition. He said that excretion of toxic substance due to 11 years of smoking took almost 31/2 years.

Hence the trust between the healer and the patient would make the individual to continue the treatment until one would get relief from the sickness. The time required for recovery would depend on the nature of the problem.

6.7. Role of Media and advertisements in promoting remedies for Diabetes

The Television programmes such as Naattumaruthuvam in sun TV, Parampariya Vaithiyum – Zee Tamil and the doctor's interviews in several TV channels would give people number of herbal remedies for diabetic condition and its preparation. It is observed that people would also other sources of media such as Newspapers and magazines. 'Pasumai Vikatan' is one such supplement of vikatan newspaper used by few of the participants. The information related to treatment of diabetes is widely circulated through social medias like 'Face book', 'You tube' and 'Whats app'.

There are screening programmes or camps conducted by several private hospitals and they market their health packages among people at risk and who are diabetic or hypertensive or might fall into the criteria of diabetes or hypertension or cardio-vascular diseases.

It is observed that one or two participants have started to grow some herbal plants like 'nithyakalyani' or 'insulin leaf' in their home garden. One of the folk healers started growing insulin leaves and selling them for the patients with diabetes. Folk healer used to treat small ailments and take less money from their villagers. But after started treating diabetes with insulin leaf, he started charging more and negotiate to give Rs. 500/ every month. One of the patient's wife, a construction labour said that *"what to do we don't have place /time to grow those plants and all in our house, we have to pay this man"* (Mr. A, Mullikulathur, 24.04.2016).

6.8. Interactions between Patients and the Health Care Providers /Health Care Facility

It is observed that the responsiveness of the health services importantly the responses of the health care providers are considered as an important aspect, which the patients expect to be more accessible than any other aspect while availing health care services. But the interplay of awareness, education, and knowledge of the health care providers puts them down and, in a position, to oblige the health care providers' advice (order). The power hierarchy which is related to the difference in the levels of education, knowledge and practice between the patients and the health care providers influences the communication between the patient and health care provider.

For example, Mrs. PB, 65 years from BCMs said that the nurse at one of the government health facility always irritated with her and would comment that *“how many times do I need to tell you, you never understand when to take what medicines, just move out and let the next patient come in to collect the medicines”* (Mrs. PB, Kamaraj Nagar, 24.12.2015). Mrs. PB said that for two to three years she did a blunder that she consumed a tablet before breakfast and which she replaced with another supposed to take after breakfast. Hence, she felt dizzy on several days after consuming the food. Once she was in queue to collect her medicines at the hospital. Then a woman next to her took medicines before food. She was taking a different tablet before food while both of them were given the same tablets for diabetes. Then she became aware of her mistake and hence approached the nurse in order to clarify the doubt. But she did not receive the expected response and hence continued to express inability that *“they are well educated, but we are not”*, *“I am not young like her”* and another comment which made her to compare with a well dressed up woman for whom the nurse had responded. This indirectly influenced the *“humiliation”* as she perceived the situation.

Whereas at RUWSEC (NGO clinic), the doctor used to explain the patients that *‘chinnamathirai’*(small tablet) would reduce the sugar and *‘periyamathirai’*(big tablet) would control the sugar and which needed to before/after the breakfast. (Interview with Dr. V, 25.01.2016) (The tablets are metformin and glibenclamide)

In another instance Mr. J from Suradimangalam said that he found the doctor at the primary health centre was good whereas the nurse used to behave a bit rudely. The reason was the doctor had called him over phone during night to remind about his daughter’s injection which they supposed to take the next day for dog bite. Here also the power hierarchy played a role but in a different way as the doctor was more educated and considered to be more knowledgeable and hence higher than the nurse in the context of care provision.

This kind of dynamics could be understood well when we tried to triangulate the same situation. When the same situation was mentioned by a nurse in the health centre that how she happened to show her face with the patients when she could not spend enough time with them and explain what they required to know. Because she was overloaded with the routine of the health centre, she could not perform some other activities and she had to prioritise according to the need.

6.9. Human resources and financial constraints

The medical officer at the Primary Health Centre said that the postings against sanctioned post were not done. It is observed that only 2 staff nurses (RCH) were posted against 3 sanctioned posts of staff nurses (RCH) and 1 NCD staff nurse was post against 1 sanctioned for that health centre. Among the two posted, the RCH nurse was on long leave and another was diverted to perform the duty at the block Primary Health Centre. Hence the staff Nurse (NCD) was then pulled to perform the activities related to RCH. The staff Nurse (NCD) mentioned that she had taken up night duty three months continuously as she was asked fill in for the staff Nurse who was posted for night duty. Then slowly she confronted the Medical officer and the District authorities to post a staff Nurse from other centres or an ANM for night shifts alternatively.

The salary was not raised despite the Nurse working there for continuous five years. The nurse (RCH) used to get night allowance of Rs.1000 every month. But in case of the Nurse (NCD) despite she performed the night duty she was not provided that allowance. The salary of the hospital worker is comparatively higher which is closer to double their salary. As one of the nurse mentioned

“Even the hospital worker is getting a good salary, closely double like mine, we too have family, we need to run it. I could have got more than this by now if I could have worked there in the private hospital. But in order to get a permanent position in the government sector we had to suffer like this” (Mrs. J, Sadras, 17.04.2017)

It is observed that they were posted on contract basis with a starting payment of Rs.7500. It was also said to them that they would get a permanent position after the completion of two years of their service. But the post was not confirmed despite a nurse worked five years.

The staff nurses who were trained and posted for the NCD clinic had different experiences which affect them psychologically and in turn would have an impact on the behaviour of the organisation (here the primary health centre).

6.10. Lab facilities in the provision of diabetes care

The Nurse (NCD) also faces the work dynamics when she had to do blood sugar tests when the Lab Technicians were not posted or the technician who posted as part of other projects had to perform the routine blood sugar tests. If the nurse had to perform job related to NCD,

then she could master it well from screening to data entry in HMIS. But she had to perform RCH activities and also would run to perform the leftover activities of NCD project. Every week they are supposed to enter the screening data but both of them found it difficult to perform the same within the stipulated time.

The issue of availability of Lab technician is found to be handled somehow at Sadras PHC. As mentioned earlier the lab technicians would visit the primary health centre at Nerumbur twice in a week on Tuesday and Friday respectively. It was observed once a woman came around 10.30 am to have a blood sugar test for first time to the primary health centre. But she was referred by the lab technician to make her visit next week. He could not perform fasting blood test then as it might show very low level of sugar. But later when the lab technician was interviewed, he raised the same concern that there was more chance of patient not attending the health facility next time for a blood test. If a permanent Lab Technician would be posted, then the chance of her re-visit immediately the next day would be more compared to chance of her visit the next week.

6.11. Continuing same medicines with the same prescription for several years

It is found that the patients attended public health facilities were treated with metformin and glibenclamide and the same treatment would continue for several years. The only change found was in the increase of dose of medicine when the blood sugar level had increased. Very few were found to have put on insulin when the blood sugar level was high by referring them to the tertiary care government facility (CMCH). The level of bodily discomfort made the patient to shift from public health facility to private or NGO or CMCH.

While the patients used to visit the private health care providers would visit the doctor, only when they would experience any sort of bodily discomforts or to show the blood sugar report. Paying doctor fee was found to be one reason which would limit the patient to see the doctor every month. The patient would continue the medicines by buying it in the medical shop regularly without monitoring the condition for several months. The cost of illness was found to have a strong link with the plurality of treatment or shifting of private health facility to public health facility or NGO clinic either as a parallel or additional treatment choices. This was mainly seen among the landless and marginal labourers. It was shown in the first part of this chapter. But there were few private practitioners referred their patients on the basis of financial constraint to the government health facility either for treatment of diabetes or complications.

6.12. Retaining the patients to get treatment in the same private health facilities

“I would not prescribe more blood tests to the patient when he/she would visit me for first time. It might make them discontinue their treatment. So, I would start with basic treatment first and then after seeing the prognosis, I would ask the patient to go for a blood test if there was not progress in terms of health.”(Dr. .Tirukalukundram, 21.02.2016)

From the above narrative it can be interpreted that the doctor is either concerned that he might lose a patient or he could not follow his/her health condition.

A different aspect was shared by a woman about how one of the private health care providers to retain her there in his clinic for treatment. Mrs. D from Perumbedu (08.02.2016) said that she took treatment from one physician since diagnosis and then she shifted to another doctor as the previous doctor would not be available in his clinic for some days as he supposed to work during day in the government hospital. Later she happened to attend the same doctor for some other illness and she shown the medicines which she used to take regularly for diabetes as prescribed by another doctor. Then he commented on it that “what for this medicine? this is like mud” “ithuethukku..mannumaathiri”. Since then she shifted to him for her diabetes treatment.

Since then unless she need any urgent care she would never attend any other hospital. She said that it would be difficult if she would face any emergency in his absence as there was ‘good rasi’ with this doctor as she could recover sooner when compared to others.

There are instances when a kind of anxiety is caused to the patients when they were asked to follow certain advice on the condition that they would not be attended again by the health care provider if the advice was not followed.

One such occasion was shared by Mrs. S from Suradimangalam. She used to take treatment from Nerumbur PHC. When she went to the PHC with a complaint of discomfort/giddiness, she was found to have high blood sugar. Then she was referred to the CMCH to get treated and further an opinion to continue the treatment there at the PHC. She was told that until she would attend the specialist at CMCH and get an opinion for further management, she would not be attended by the doctor at the Nerumbur PHC.

But she was not in a position to go to CMCH from her village then. As she was in need of an attendant, she did not go to the health centre again. She took rest there at home. When she

tried to visit the primary health centre again, she was asked to check her blood sugar status and also without she collecting the opinion from CMCH, she was not attended again by the doctors there at the Primary Health Centre.

The general practitioners at the private health facility have an established network and the referral system to handle the secondary complications. But the process of emergency was challenging for the patients who had to travel long from the villages and who could not afford for the expenses then.

6.13. Handling Emergency condition of diabetes

It was also found that both the public and private health facility at primary level or secondary level could not handle the condition of hyperglycaemia and they would refer immediately to the CMCH or any specialty hospital.

Mr. PO, a 41years, a schedule caste, male patient who studied up to the 10th standard was deaf and dumb. He was diabetic for 2.5 years then. He used to take treatment from CMCH. His regular medicine was insulin - Actrapid 10-0-5 and Mandtrid 15-0-10 then. His wife only responded for the interview. He also tried to respond to some. His wife shared about an episode of high sugar occurred after dinner. When they went to the Government Hospital, Tirukalukundram, he was referred to the CMCH as they did not have specialist there. But it was late then and they could not leave the children at home separately in the night time and hence they came back home. They would need to depend on the public transport to return from the hospital after treatment. Hence, they decided not to visit CMCH and returned home. Then he himself took insulin once again, took rest that night and then he went to CMC the next day and got treated for high sugar. She said that he had insulin shot then only before dinner. But she wondered how his sugar got increased suddenly and she could not identify the reason yet. The fasting blood sugar level of 218 mg/dl and post prandial was 293 mg/dl were found to be his blood sugar report then.

6.14. Other constraints or facilitating factors which play an important role in the provision of diabetes care.

The important concern raised by the health care provider at the NGO clinic is discontinuation of medicines. A specific case was shared by the doctor in which the patient discontinued the medicine after getting treated from a (non-professional healer) who used to treat the patients by pressing some points. Later the patient visited him in the stage of non-Ketotic coma and he treated the patient and put back on regular Allopathic treatment.

The other concern raised by the doctor in the NGO was about the paucity of funds to perform tests like HbA1c, might be useful for better management. The NGO would conduct annual camps in screening for complications such as eyes, heart and kidney. The number of patients they serve might increase and which depend mainly on the availability of funds.

The similar reason 'paucity of funds' was mentioned by the medical officer at the primary health centre that whenever they were allotted with enough fund, they used to conduct the specialty camps, otherwise it would be skipped.

The Siddha doctor at the PHC (Sadras) felt good about the co-location of Siddha and Allopathy clinic in the same health facility. She felt very good when the patients are referred by the Allopathy practitioners to her clinic mainly for ortho problems or foot ulcers. She mentioned as they told as "Go and see siddha doctor, get 'mathanthailam' used for foot problem n diabetics. As she was there in the government sector around two decades, she could the change that the 'reducing hierarchy' among them but with limiting boundaries.

The health workers at RUWSEC felt conducting 'support group' meetings have clarified many doubts regarding diabetes among patients. It is observed that RUWSEC used to conduct 'support group' meeting every month for the patients with diabetes. There would an education programme organised each time with a focus on any aspect of diabetes /hypertension / complications. There would be discussion about their experiences with their condition / medicines / practice of home / herbal remedies. A special food item would be prepared and served with different grains / millets. The other important concern raised by the health workers was the provision of less wheat in the public Distribution Shops but the patients were advised to consume wheat as compared to rice. Hence, they mentioned that the policy need to be changed in the PDS for distribution of locally produced items.

Few of the Village health Nurses raised the concern about checking blood sugar in the field level is important as they could educate the patient when they reach then at the sub centres. They felt it would be better if they are provided with the glucometer.

It is observed that the patients had to visit CMCH in case if their blood shoots up very high or they need any advice /support related to insulin, they need to attend tertiary health facility.

Hence the training of the primary health care providers in this aspect would support the patients in a great manner.

While observing the majority of the participants had shown contrast picture of how they tried to follow the doctor’s advice. The same is compiled in the following table 6.4.2. As the majority follow the system of Allopathy, it is tried to have a contrast picture of what are the advice given by the Allopathy practitioners and what is the actual picture of follow-up. The advice by Siddha practitioner is also added as the next most system followed system Siddha. This is represented in the table 6.2 as follows

Table 6.2: Advice given vs. Advice Followed

Broader domains of treatment	Treatment Advice given by the Health Care Provider (Allopathy)	Treatment Advice given by the Health Care Provider (Allopathy)	Treatment Advice followed by the Participants (Landless labourers / marginal farmers)
Food/ Diet	Balanced Diet Low Carbohydrate (decreasing rice consumption) Alternative - wheat High Fibres (increase vegetables consumption) Small portions / for six meal pattern Decreasing non-vegetarian consumption(a small portion of lean meat is recommended) Regular Timing for meal / intake of medicines	Importance given to small grains but not restrict to that alone. Based on vaatam, pittam and Kepam, restricted few items (eg. Chicken /reduce the heat)	Food –difficult to have 3 meals a day Skipping food and hence skipping medicines Only cereal with less price – rice (affordable) Purchase of wheat / processing and preparation requires time and labour Vegetables – consumption based on availability and affordability

Medicines	Lifestyle modification One OHA Combination therapy Addition of insulin As per the level of blood glucose Should not go for other systems of medicines	Madhumeaga choornam – 48 days Concoction of ‘Nilavembu’ - gradual decrease- every day – then weekly twice/ ten days once/ gradual decrease in the medicine Promote consumption of herbal remedies too	When they happen to skip food / they would also skip medicines
Monitoring of blood sugar	Monitoring of Blood sugar / three month once	Not very keen in blood sugar monitoring	Availability of lab technicians - only for two days in the PHC Two days - to do the blood test one day/collection of - Loss of an extra day at GH, Tirukalukundram Blood test and report collection – same day at NGO clinic/ private labs and hence pay for the blood tests and hence majority tried to visit there to these facilities for blood tests
Physical Activity	Regular Physical Activity – Walking /Exercise – minimum 20 - 40 minutes / day	-	Continuous physical labour made them to question the need for physical activity separately (mainly Landless Labourers and marginal farmers)
Stress Management	Sometimes doctors do mention about the stress management	Tried to explore psychological/ familial relationship (Importance is given here in homeopathy too)	-

Source: Field Study, 2015-2017

The following are the health care providers interviewed from different Health Facilities are represented in Table 6.3.

Table 6.3: Details of Health care providers participated in the in-depth interviews

Health Care Providers	PHC, Nerumbur	PHC, Sadras	Private Clinics, Tirukalukundram	RUWSEC Clinic
Practitioner-Allopathy (MBBS)	2	1	3	-
Practitioner-Allopathy (MD Community Medicine), trained in Endocrinology	-	-	-	1
Practitioner-Siddha (BSMS)	-	1	1	1
Practitioner – Siddha (by training)	-	-	1	-
Açcu Healer	-	-	1	-
Sector Health Nurse (SHN)	1	-	-	-
Staff Nurse(NCD)	1	1	-	-
Lab Technician*	2			
Auxiliary Nurse Midwife (ANM)	1	-	-	-
Village Health Nurse (VHN) (interviewed)	3			
VHN (Focus Group Discussion)	8	-	-	-

Source: Field Study, 2015-2017

CHAPTER 7
DISCUSSION AND CONCLUSION

7.1. Conceptualization and Implementation of the research

This research “Social Dimensions of Coping with Type II Diabetes” is conceived and conceptualized in order to study the broader social aspects of coping from an interdisciplinary approach. From the literature review, it can be said that earlier studies on coping with diabetes were studied mainly through quantitative analysis. The aspects of coping were reduced to individual factors and analysis was done between the selected factors that facilitated coping. The focus then was more on individual life style and behaviour and hence the concept ‘adherence’ was widely used in studying how people cope with a chronic condition like diabetes. Similarly, diabetes was conceptualized from a bio-medical or clinical perspective. The widely used disciplines of epidemiology, demography and health economics have used mostly a quantitative approach. Very few studies have engaged with the qualitative aspects of coping in everyday life. These studies are mostly from the disciplines of sociology and anthropology. While the quantitative studies give an understanding of the prevalence, distribution and variations, it does not capture perceptions and experiences of the diabetic and his family.

In this thesis diabetes is conceptualized as a condition that needs a broader approach and analysis than merely a clinical problem. As it is a life-long and chronic condition, it forces us to go beyond a single discipline in studying the process of coping with diabetes. Hence, in order to address the research objectives, an interdisciplinary approach is used. There are several concepts which are borrowed from several disciplines such as epidemiology, clinical medicine, Biochemistry, Sociology, anthropology, Economics. Social Psychology in order to capture the dynamics of the bio-social interaction and its effect on the experiential aspects that determines coping at different levels - the individual (subjective), Family/household and at the health care services. Each of this acts as a determinant and interacts with one another that affects coping with the disease.

This research has employed both a quantitative and qualitative approach. The primary and specific objectives of this research are as follows.

Primary Objectives

- To study the social dimensions of coping with diabetes among people living in rural Kancheepuram

Specific objectives

- To study the socio-economic distribution of people diagnosed for diabetes in selected villages
- To study the illness experience and treatment seeking behaviour of persons diagnosed with diabetes
- To study the availability, accessibility, affordability and acceptability of health services for treatment of diabetes
- To understand intra-household dynamics in everyday coping
- To understand the interaction of caste, class, gender and religion in coping with diabetes
- To examine the variation within and across caste and class groups in coping pattern
- To explore the understanding of diabetes and its treatment among health care providers accessed by the patients

My earlier research on the ‘Social Dimensions of Type II Diabetes: An Exploratory study in Chennai’ was the formative study that helped to conceptualise my doctoral thesis. This study provided insights into how individuals affected with diabetes perceive their condition and how it influences their treatment seeking behaviour. It also provided an understanding that there are individual and structural factors that explain perceptions and treatment seeking. Given the chronic nature of the disease the study highlighted the choice of plural systems and therefore the multiple resort patterns to treat diabetes. This study also gave insights into the variations in coping with diabetes across class, caste and gender. After our explorations in the urban context I was curious to study how people in low resource setting would seek care for diabetes? How do individuals who are involved in agriculture in rural areas handle this chronic disease? How does the availability, accessibility and affordability of health services act as determinant for treatment seeking? These are the questions that formed the core of my doctoral work.

So, in order to conduct this study, we had to identify persons with diabetes in rural areas. We observed that diabetes screening programmes were happening in health districts of Tamil Nadu as part of the activities of Tamil Nadu Health Systems Project since 2008. Hence, we

approached several government health authorities in the state of Tamil Nadu in order to access the data base of the persons affected with diabetes. But we have not received timely response from them. Meanwhile we approached Rural Women Social and Education Centre (RUWSEC), a Non-Governmental Organisation (NGO), which had a data base on people with diabetes in its' work area of 25 villages in Tirukalukundram block of Kanchipuram district. Hence after obtained permission from the members of RUWSEC's Executive Council to access the data, we purposely selected those villages to conduct this PhD research. A total of 252(148F, 104M) persons with diabetes were surveyed during the first phase survey among 252 persons with diabetes. Then during the second phase the patients were again purposively chosen among 54 patients (32F, 22M) to conduct in-depth interviews using the interviews. The representation of patients based on caste, class, gender and severity of disease was ensured in selecting the patients.

7.2. Socio-economic profile and Prevalence of diabetes

The study district Kanchipuram, one of the highly urbanised district (64%) compared to the state (52%), but Tirukalukundram is less urbanised as 46% of it's population found to live in urban areas and 56% of the population live in rural areas, which is comparatively higher than the district level (36%). There are evidences that increasing urbanization also had shown positive relationship with the presence of NCD risk factors (Ambady R et al., 2008, Allender S et al., 2010; 2011). Current study of select villages in Kanchipuram has shown around 6.5% (5.7%M, 7.3%F) prevalence of diabetes. An ICMR-INDIAB study had shown total of 7.8% prevalence of diabetes in rural areas (Anjana RM et al., 2011). When they segregated into high and low-economic population, it has shown 6.5% among people with low socio-economic status and 8.6% among people with high socio-economic status. As the majority of our study sample belonging to low socio-economic status, the overall prevalence of our study is consistent with Tamil Nadu's rural prevalence among people with low socio-economic status.

The land holdings and labour by the different caste groups will give us broader idea of the socio-economic status of the different caste groups in the select villages of our study. The land distribution among the study sample shows that about 68% of the landless labourers are from SCs. Whereas of total 16% marginal farmers, roughly one-third (30.3%) belong to the MBCs. Majority 71% of other caste group (mainly Reddiyars) is in small and middle peasant

group and the persons involved in or relieved from government job/professional job holders are among BCs that account for 38.9%. This data is represented in table 3.1.5.

If we look into the current study's caste wise prevalence, the male sample has shown 5.7% across SCs and MBCs and 4.5%BCS, 6.2%BCMs (Muslims mainly Labbai) and 8.9% OCs (considered to be general category) respectively. It is seen that the three female groups SCs (6.6%), MBCs (6.7%) and BCs (6.2%) have shown similar prevalence, but 8.6% among OCs and 30% BCMs that is widely differ from other groups (see Table 3.1.6). As mentioned earlier in the chapter 3it was shared by the investigators the participation of Muslim men was lesser and that might be the reason for this wider difference between males and females of the Muslim population. Other studies conducted in India also shown similar results in contrasting the Muslim population having higher prevalence of diabetes compared to other ethnic groups (Akhtar SN and Dhillon P, 2016, Kanungo S 2016). The study conducted among Muslims by Shah A and Afzal M (2013) had shown the total 16% prevalence of diabetes. Sheik population had shown a higher prevalence 23.2% compared to other Muslim population Syed (10.4%), Pathan (14%), Moghul (18.4%) and Hindus Meitei (14.6%) and Naga (10.1%). All these Muslim population referred in the Manipur study is belonging to the general category whereas the Labbai Muslims are belonging to backward class in Tamil Nadu. Hence the prevalence is higher among the lower caste than the higher caste groups among Muslims.

7.3. Presence of Complications and Co-morbid conditions

There is not any uniform pattern observed in the prevalence of complications/co-morbid condition. Around one-third of total study sample has one or other complications. There is no overall gender variation but females have shown slightly higher prevalence of cardiac problem (6.1% vs 3.8% males). This pattern is corroborated with the study conducted by Joshi RS (2014). It is observed that overall caste wise prevalence of complications is comparatively more among MBC (42.7%) and BC (41.7%) than among SC (29.5%), BCM (33.3%) and OC (28.6%).

The most common co-morbid condition is hypertension that is about 25.8% with no significant gender difference male (24%) and female (27%). The total prevalence (26.5%) of hypertension is consistent with a National representative study (Geldsetzer P, 2018). This study has shown a different picture from other national level study, 5.9% and 30% of the poorest wealth quintile in the rural areas had diabetes and hypertension in the age group older than 40 years. Whereas ICMR-INDIAB study shown that the people among higher socio-

economic status has shown higher prevalence of diabetes than the people among lower economic status (Anjana R et al., 2017).

Among the Patients who attended the government health facility, very few are referred for albuminuria (kidney function test) and lipid profile. But hypertension is checked during monthly visits made by the patients. The less prevalence of complications among certain caste group (SCs) might be attributed to the unperformed screening for complications. The patients who used to take insulin among the SCs used to visit tertiary health care facility at the district. About 44% of the SCs are attending the government health facility, whereas 52% of the backward caste group used to attend government health facilities. They used to attend tertiary health care facility in the district and state headquarters for screening of complications. Around 39% of either study participants or the family members of the BCs either involved in or retired from the government job or in the professional jobs like Engineers. They also avail their health benefits from public tertiary hospitals such as ESI or other referral hospitals as part of the employee health scheme. So, we can see that who are in a better position to use what level of health facilities and when and how frequent, all these determine the treatment management or health seeking of the study sample. The participants other than scheduled castes are purposively studied to contrast the pattern of treatment across various caste group as well as class group within and between the caste groups.

Moreover, the presence of complications like foot ulcer, un-healing wound which might reduce one's ability to work and further affects the independent status. This might increase the feeling of worthlessness or powerlessness. This may be perceived powerlessness or experience in real life situation. This feeling of worthlessness or powerlessness is seen in women who are elder adults and who happen to perform less because of their illness condition such as foot ulcer/cardiac problem. Mrs. P, Kunnavakkam and Mrs. K, Pattaraikazhani had such experiences and hence the feeling of powerlessness is prevalent among them. There are studied showing the presence of perceived powerlessness among the patients with the foot ulcer (de Jesus Pereira MT, 2014). Another study tried to figure out ill-health itself is as feeling of powerlessness through essence of ill-health. It is further argued by the author that 'destructive feelings of powerlessness, alienation, anguish, shame and the individual's autonomy and existence are threatened'.

Hence this is important to look into the individual's perception and experiences of health are important while studying the coping of a chronic condition like diabetes.

7.4. Process of Coping – A continuum from subjective symptom experiences to the individual’s interactions with the family / health care services

Now the focus here has given to the process of coping from the perception of illness, diagnosis and treatment seeking for diabetes. This process is a continuum of falling ill, then being sick, recovering back, learning and managing the condition to live a life with a chronic condition with special needs and care. The symptom experiences show that about one-third of the study sample perceived the bodily discomforts before diagnosis of diabetes. They have made a logical decision in treatment seeking, to start with the process of diagnosis. So, when the ‘intensity’ of the symptoms increased, the ‘worry awareness’ automatically drives the individual to seek treatment. This has shown that intensity and severity of the symptoms have an effect on the behaviour of treatment seeking. But the social condition of the patient is also considered as a major contributor in determine the treatment seeking. Mrs. M, experiences have shown us both the behaviour. When the intensity of her itching increases, she could not tolerate it, she started with home remedies, it did not help her, hence she tried to visit the health facilities, but when her recurrence happened, she had to look for the specialty health facility.

7.5. Decision on treatment/coping process not solely depends on the individuals affected but it is relational

We need to understand the underlying process of treatment seeking. When we seek care/when people offer care, the decision would not involve the individuals affected alone. For instance, when Mrs. M wanted to visit another health facility with her sister, she was not allowed to go as she had to involve in the farm related activities. The decision is partially or impartially her husband or the existed situation of responsibilities. Here we could see the dynamics between the work / husband’s decision/social support and which determines her behaviour of treatment seeking. Similarly, the multiple roles at household / outside importantly in case of women determine the treatment seeking. This similar pattern can be seen among the women involved in landless labourers and the marginal farmers mainly. It makes them compromise with their needs but also to care for health. There are studies contrasting to this study. A study among African American women tried to show that how the multiple roles play a role in keep women active and in turn they take care of their psychological aspect and which would further keep the physical health in a good condition (Verbrugge ML, 1983). There are studies which

pointed out the multiple roles play a protective role on health functioning of the African mothers through accumulation theory (Black RA, 2009).

But the studies done by Mendenahall (2010;2012;2014;2017) among poor Mexican Americans and other population have shown the connection how people experience their lives every day, their poverty, work pattern, multiple roles at home and work had played an important role in taking care of diabetes. Kleinman (1980; 1988) also revealed the interplay between the patient and their social context, their psychological well-being. Both the authors brought out the multiple layers of social factors and how their intertwined nature different layers which influences different spheres of life and which further worsen their uncontrolled sugar in case of type II diabetes. Raphael D (2003) brought out how the material deprivation played a significant role in the incidence and management of diabetes. The current study has shown that the material deprivation mainly affordability in purchasing for everyday meal is a challenging area importantly in the case of Mrs. R, Mrs, M and Mrs. Sh affect their food intake.

Kawachi I and Berkmen L (2001) have argued that the social connections with fulfilling the social roles would enhance the feelings such as self-worth, belongingness, security, which further promotes the positive functioning, self-efficacy for maintaining healthful life styles. This can be interpreted for the participants who are in the class IV and class V of our study population who used to try fulfilling their required everyday needs of diabetes and manage their health condition in order to control their sugar and also their complications.

7.6. Stress / Distress as an important cause of diabetes

Female participants of the study mainly associate their onset of diabetes with their every day tensions in life, spousal violence, accumulated worries/sadness, Loss of asset or huge financial loss and Death of near and dear ones. Similarly, there are situation or phases in life which men associate their onset of diabetes are mainly of employment issues, income issues, routine and nature of their job. This finding is similar to earlier study conducted in Chennai. This also shows consistent results with other studies conducted among Mexican American population (Martinez M and Herrera R, 2002; Mendenhall 2010; 2013).

Across caste, there is at least one woman reported about their suppressed emotions out of their married life and which has accumulated over a period of time. One of the participants said that 'If I would recollect those memories, I would feel like somebody hold my breath' 'It is

like, that sadness would block my throat' (dhukkam thondaiya adaikura maathiri) – Interviews conducted in the villages of Tirukalukundram, 2015-2017). As the majority of the landless labourers are belonging to the Scheduled Caste, it can be interpreted that their priorities in life get into the spheres of livelihood, income, food, and housing. But in addition, they also mentioned about this problem private sphere such as spousal relationships which creates lot of problem in the family.

7.7. Plural availability of treatment and ambiguity in choosing the treatment

It is found that nearly 18% of the participants were taking treatment from other systems of medicine such as Ayurveda, Homeopathy, Siddha, Accu Touch. Few have approached folk healers and spiritual healers to heal their illness. This again shows the relational behaviour of the patient and their interconnectedness with the plural availability of the system. At one point it creates a tension between the scientific determinism and the social determinism wherein the participants who used to take other systems of medicines would get into an ambiguous phase 'which is right medicine? Which is the best medicine which treats me better? Do I go for allopathy or siddha or any other system of medicine? This tension is created by the availability of the multiple sources of remedy. A study reported from NSS 2014 by Rudra S et al., (2017) has shown that about 6.9% of the patient's have utilized AYUSH services in the reference period of two weeks. The absence of consensus among different systems in treating diabetes is a crucial area. Mainstreaming AYUSH also needs ethical considerations to address several dimensions like what level of integration, for what kind of ailments, how much is feasible, the good/bad in standard guidelines and so on (Gopichandran V and Sathish Ch., 2012). As every health care providers importantly all the practitioners of different systems of medicine have their own principles of practising their treatment discipline. For instance, one of the practitioners said that he may not actively refer the patient to the alternative systems of medicine and if in case anyone is interested, then he will refer them, He never entertains his patient to visit the practitioners of other systems as he said he cannot take a risk of dealing with a patient who take multiple remedies and which is also practised without professional expertise/evidence.

7.8. Social networks in coping with diabetes

Sometimes, it has been seen that there is logic for every action and response from them. The referral of a diabetes patient to any treatment by his or her neighbour or a relative or a friend or a peer network give us the picture that their previous experiences become an evidence in

referring others to the same treatment. This also give us the evidence that how a strong network can be built within a community to perform common activities. The case of Ammanampakkam has shown how the communitization is happened on its own in case of visits to Accu-Healer. Similarly, the sharing of medicines and storage of insulin in neighbour/relative's refrigerator also shows how diabetes occupies the people's life and caring for diabetes become an everyday process in lives of these people.

This process also makes people more aware of the condition of diabetes and it's everyday coping with diet/physical activity. For instance, the youngsters in the neighbourhood of the patient help him or her to inject insulin every time. In one of the villages, four to five men with diabetes started to discuss about their diabetes condition at initial days, later they started and continuing everyday walking.

7.9. Determinants of everyday coping

A common pattern can be seen across class. The working class landless labourers have shown that their priorities on livelihood, food, children education, daily family expenses, indebtedness, secured shelter conditioned them to focus on the most needed things to lead their everyday life. These results are consistent with the earlier studies conducted in Chennai (Arutselvi, 2013) and Delhi (Mendenhall E 2010;2012) Until they feel the bodily discomforts such as low sugar/giddiness/fatigue, diabetes is not considered as part of their life/everyday activity. To some extent, the same process can be observed among the marginal farmers. The condition of the dependent elder adults is worsened as the other family members ignore/neglect their health condition and provide meal for sake of providing. The place of residence also plays a role in accessing the health facility. The elder adults would always ask their children or someone else to get their medicines from the health centres.

The gender variation is significant in terms preference of food item, purchase /distribution of food, visits to health facility, monitoring of blood sugar and monitoring of complications like foot ulcer. The ignorant attitude of the male towards female, her dependency for her treatment, her less performance during sick days receives the ignorant attitude from the men of the family especially husbands. The patriarchy is rooted in every aspect of life of a woman. Mrs. M and Mrs. V expressions are very appropriate here. Despite they earn through NREGA or other labour, women would not spend for her and spend only for the family. But she would expect her diabetic husband to take care of his diabetes in a private health facility and monitor his condition regularly, healthy diet and she ensure that everything he follows regular on time.

The social support/social relationships (spousal) are significant in facilitating/constraining one's treatment. For instance, Mr. G, Kamarajnar suffered from chronic kidney disease and hence he was in need to visit the specialty hospitals weekly twice for dialysis. The dialysis is taken care of the chief minister health insurance package. But he has to take care of his transport and food every time he visits health facility which is located very far from his village. His immediate tertiary health care facility also has its damaged equipment for dialysis.

So, he used to travel to another medical college and hospital for which he needed to travel almost 3 hours to reach. His wife is the only person who used to spend on him by going to NREGA or any labour she would get every day. Most of the time she would get the job of a construction labour. Before he fallen sick, he used to earn a lot, he used to consume alcohol a lot but he would never give money to his family and once this happened to make his son discontinue his B.E. course because he did not pay his college fee. So, his son would never help him. Wife is observed to show concern on him as he is her husband. The study done among urban poor in Karnataka has pointed out the nuclear family structure and intergenerational conflicts as one of the important constraints in health care access of elder adults (Bhojani U et al 2013). Whereas Mr. S, Suradimangalam, when he had to undergo cataract surgery in one of the specialty hospitals in Chennai, he stayed in his daughter's house in Chennai till he gets over with his treatment. He would stay there if he had to visit the hospital for any kind of continuous treatment. The social ties or connection plays an important role in his case as he was not in a need of doing up and down to his village. He also paid around 23,000 from his Employee Health Insurance Scheme. But Mr. G had to spend for his travel minimum of Rs. 100, for food Rs. 150 for his food all three times in a day to attend his dialysis every three days once. He had to spend on his dialysis kit of Rs. 500/- to Rs.750/- sometime as they would tell him to pay this fee because the amount which they had claim for his treatment was over.

From the above two cases, we can also interpret socio-economic position, source of livelihood, place of residence, severity of the condition, social relationships /support within the household determines every day coping with diabetes. There are other studies that corroborate the findings of this study (Shobana 2002, Kapur A 2004, Viswanathan V 2005, Gopichandran V 2012).

When we see the everyday consumption pattern in general, majority preferred to have rice as it is considered as staple food but when we look back few decades earlier, people then seemed to consume more of coarse millets and grains mainly the horse millet along with rice. But over a period of time, rice has occupied the place of staple food item. There is also a class notion in consumption of horse millet. It is widely consumed by the working class whereas the landlords used to have rice most of the time. Hence it is observed that there is unexpressed notion among the people that ‘rice is for rich people’ ‘raagi is for poor people’. Majority of the working class were from the scheduled caste. Hence now they sort of developed a dislike towards ‘raagi’ because they were served gruel of ‘raagi’ when they were working as labourers. As one of the participants shared that they earn enough to have food but they could not eat what they wish and which were considered as food of the rich earlier. On the other hand, people also expressed that they do not get millets in the PDS, they get wheat other than rice and which they are not used to. It is found that states like Karnataka started giving millet²⁹ since 2015 and recently the centre also announced that it would be added millets for public distribution in states through PDS³⁰.

The health care providers used to instruct them about the quantity of food consumption. Most of the participants who would perform more of physical work tended to eat more compared to those who did not perform any physical activity. Hence if they would try to control intake of food, then six meals would be an appropriate pattern to keep the blood sugar normal as per the doctor’s advice. But there were participants who could not eat enough food because of their socio-economic position.

7.10. Controlling Food or Diet?? – Tight Control or Poor control of Sugar

One of the observations is that many of the participants experienced hyperglycaemia /hypoglycaemia/ tiredness/fatigue frequently. This study has revealed that how participants from lower socio-economic status could not afford to have proper three meals in a day either due to financial constraint or everyday routine full of work had experienced hyperglycaemia or hypoglycaemia. Now this is a different case given below.

“I used to take oats only – used to take medicines 3 times and sugar level was 32 mg/dl. I was experiencing fatigue and could not sense what was going on what, started

²⁹ www.caravanmagazine.in/vantage/millets-still-not-under-pds accessed online on 14.07.2018

³⁰ www.deccanherald.com/content/666770/centre-bring-millets-public-distribution.html accessed online on 14.07.2018

behaving indifferently. People told that my mind got changed “Gonamaatramaayudichu”.But it was entirely due to low blood sugar”(Mrs. S, kunnavakkam, 24.04.2016)

She continued

“People used to tell that those who eat more food..more sweets would get sugar I don’t know why I got this I never used to eat more food..moresweet..but I don’t know why I got this might be due to my sadness in my heart, I would have got diabetes (manasukullakavalaithanalathan sugar vanthurukkumnuninaikeeran..)”. (Mrs. S, Kunnavakkam, 24.04.2016)

It is found that 9% of the male participants stopped taking medicines. Half of them have their age at diagnosis below 40 years. In the initial period of their treatment, they had followed doctor’s advice and shown that they could achieve normal blood sugar level within few months (3 months) stopped the first line medicines that they were prescribed.

For instance, a man who is 39 years old and a lorry driver was found to be diabetic and advised by the doctor to take metformin. He was also informed that he can stop the medicine if he could control his sugar and found to have normal level. Then he has started following the doctor’s advice in terms of diet, regular physical activity and confirms with the doctor that his sugar is under control and feeling happy that he is not required to take medicine. But after that he gradually stopped doing his regular exercise and did not follow his diet pattern, did not check his blood sugar since he did not experience bodily discomfort. The nature of his job was also a factor to be considered here. When he was diagnosed with diabetes, he was at home and hence he could take care of all the everyday demands and achieved glycaemic control. If he would go back to same work, provided his nature of job, his food and sleep might become irregular. Not only timing as he would depend on outside food, it may not be a balanced one from treatment perspective. So, there is a chance of him coming back to the status of diabetes patient.

This is peculiar case as there was an effort by the individual to achieve glycaemic control and also the doctor-patient trust which made him to believe that he could reverse back to his normal condition. There are few men who changed their risky work pattern and tried to control their blood sugar (Mr. S, Pattaraikazhani and Mr. K, Jamberi). Similarly, there is a kind of over-trust of the doctor or anxious about bringing the blood sugar level into what is called ‘normal’. This is observed in case of Mrs. S, Kunnavakkam elaborated above.

Whereas falling into state of hypoglycaemia or low sugar in case of Mrs. R, Echanganai and Mrs. M, Mullikulathur is entirely due to conditioning of their everyday routine and tensions in life.

Hence the interactions with health care services play an important role in individual's treatment seeking in the prevention and control of diabetes. The socio-economic condition of the individual is equally important in maintaining the normal sugar level.

7.11. Individual's interaction with Health care services and it's responsiveness in the treatment of diabetes

It is found that around 80% of the participants depend on the Allopathy treatment alone. They visit public health facilities like Nerumbur PHC/Tirukalukundram GH or other private clinics/hospitals at Tirukalukundram. Majority depends on the Oral hypoglycaemic agents. Around 7% of them are taking insulin. The drugs are issued at the health facility without any struggle. Despite the duration and severity there are patients still continuing only with the first line of drugs such as metformin and glibenclamide. There are several guidelines which actually recommend six months /annual tests for screening complications (IDF 2012, ADA 2011, ICMR, 2005). But the screening for complications is poor among all the patients except those who visit specialty private hospitals.

The patients who experienced cardiac problem (3.8% M, 6.1 F), most of them were diagnosed through their symptom experiences. Around 7.7% of males and 11.6% % of females are having foot ulcer / toe amputation. It is also found that people who are found to be at risk are advised to screen for secondary complications in private clinics/hospitals at Tirukalukundram, the screening for cardiac problem is done and also referred to other specialist at the tertiary care centres. The screening for foot complication is not done or referred to tertiary care centres. But it is important to understand that screening for complications are not advised by the health care providers at Government Health facilities or Private clinics except for Albumin or a lipid profile for few of the patients. If the patients had the complaint of chest pain, then ECG is referred by the GPs. This finding is similar to other study conducted in Chennai (Tharkar S, 2015) in which screening for complications is advised to the people who attend multispecialty clinics whereas it is totally absent among the people who visited the government health facility and very few people are referred for screening complications by the General practitioners.

It is also observed that the consultation with the cardiologist is available weekly once at the clinic of a private general practitioner in Tirukalukundram. The people who are having abnormal BP or abnormal ECG are referred to this consultant by the other general practitioners in the town. It is important to note that this cardiologist is also working in the Chengalpet Medical College and Hospital. Similar network trajectory was shown in a study conducted in Delhi (Goenka S, 2002). The growth of private clinics in the study area can be seen three decades earlier only (Baru, RV 1998). As a first step they started small clinic in the town, gradually raised to big hospitals. But they are not capable of managing the emergency situation such as hyperglycaemia. Currently the patients with complications are referred to the Chengalpet Medical College and Hospital or other private health care facilities at Chengalpet for treatment. There are accessibility issues which worsens the condition of the most sufferers like females.

For instance, gender difference is very much evident in the onset of diabetes, diabetic complications and death occurrence. The females precede in all these compared to males. Then we look into the caste wise difference, the quantitative information has shown the higher prevalence of complications among the backward castes (class III) compared to the scheduled castes. But when we look into the sufferings and onset of complications the later is found to be in the vulnerable status than the former one. For instance, Mrs. K, 65 years, from backward caste group, diabetic for 35 years, developed hypertension few years ago and developed cardiac problem 1 year ago and underwent cardiac surgery. She used to take treatment in a private health care facility where they would check for ECG, KFT and lipid profile at regular intervals. They are small peasants. Before she was diagnosed with cardiac problem, she also had foot ulcer for several months as she used to walk without foot wear. Her agricultural field is very closer to their house. So, whoever would to the field, they were getting back into the house barefoot and there would be spill over of sand/mud inside the house. She also used to walk in that. Her wound was worsening and her blood sugar was not controlled. Her meal timing was irregular. Some days there would be someone to give her insulin shots. Some days she would skip that. Then slowly she started wearing foot wear inside the house. After some days, doctor took ECG and advised her to have a full cardiac check up and then later she underwent surgery with the Chief Minister Health Insurance. All other expenses up to 80,000 rupees they managed to pay from their pocket. Later they had crop failure as they cultivated sugar cane the next year and become indebted. Presently she is facing difficulties to buy the medicines regularly.

Whereas Mrs. MU, 42 years from the scheduled caste group (class I), diagnosed with diabetes at the age of 29 years. Then she also developed hypertension simultaneously. Recently she was diagnosed with cardiac problem when she developed chest pain. Both of them had more or less same age at diagnosis of diabetes. In general, we can interpret that the onset of cardiac problem is early when compared to Mrs. K. But we need to look into the life course of these two women.

Mrs. K, who got married very early at the age of 16 years, she also had gone through lots of social hardships as her mother died when she was 8 or 9 years old. Then her Aunt (paternal uncle's wife) took care of her. She was stopped schooling when she completed 6th standard. She was asked to perform all the household chores then. When she was 15 or 16 years, they got her married to her Aunt's brother. Then the real torture started as she was given trouble by her husband and mother in law. She was physically and orally abused by them. She was forced to conceive early and she gave birth to two children. She had uterine prolapse and had hysterectomy when she was 27 years. She got diabetes within 3 years of her hysterectomy. She associated her diabetes onset with her spousal abuse. She pointed to sleeplessness if she happened to recollect those memories during night.

Mrs. MU was born and brought up in moonaar (in neighbour state of Kerala). Her paternal grandfather migrated for labour reason from Tamil Nadu many years ago. Then the family started living there. She studied up to 9th standard. At the age of 18 she got married and she had several miscarriages and she gave birth to her son after receiving treatment. She was distressed then as her family members and relatives started discussing about her fertility problem. She associated her diabetes with her distress / bodily discomforts in order to give birth to a child. She had developed recurrent boils in her head and then diagnosed with diabetes in a private clinic. She was continuing treatment there for several years. Meanwhile she tried to go to TKM GH for few months and also RUWSEC clinic, but she was not feeling good, then went back to the same private hospital where she used to spend Rs.600/- for her medicines. Then a year ago, she experienced chest pain and she visited a private hospital where she was referred her to the cardiologist at Chengalpet GH. Then they decided to visit the same doctor at his private clinic so that when they would visit CMCH, he would take care of her well for instance 'allotment of bed' when they have less vacant beds. Similarly, they had taken tests and all at his clinic and informed him that they are not having enough money and requested the doctor to put them in GH. (She asked me not to record this and inform any one about this as this might defame the doctor). This is also a kind of building the connections

and short cuts to access the needed health care services. They spent a total of 14,000 rupees and they mortgaged her chain. She is continuing treatment from the CMCH. She would buy insulin outside and also an herbal product 'diaba care' (Rs.150), which she would consume with water. She would also experience breathlessness due to asthma during winter and used inhaler for that. As her husband is a lorry driver he happened to face loss of wages which would have been more than 5000 and they also fallen into indebtedness.

Both Mrs. MU and Mrs. K had gone through distressed life over several years and which they associate to onset of diabetes. The hormonal imbalance can be the mediating factor when Mrs. K shared about the hysterectomy and Mrs. K about her miscarriages and fertility treatment. Mrs. K could survive for almost 30 years without any complications but Mrs, MU survived without complications for up to 12 years. She had irregular treatment in between when she stopped treatment from private, then went to government hospital for few months and then NGO clinic for few months and later she took treatment again from the same private health facility.

The financial constraint is very much visible in Mrs. MU case then and the regular screening for complication is totally absent there before onset of her cardiac problem. If she would have had very good services from public health facility she might not have shifted again to the private health care facility. The out of pocket expenditure can be seen in both the cases. In case of Mrs. K the government health insurance helped to treat her complications. If the preventive, promotive and curative health care services are provided at the primary health care services in treating diabetes and preventing the secondary complications, the sufferings due to complications would have been prevented. Moreover, the insurance would not cover the total expenses., which would make the families fall into below poverty line. Study done by Bhojani U et al., had shown that several poor families in K.G. Halli had fallen into below poverty line (2012). There are cases like Mr. G had shown that more of indirect expenses like transport and food and which could have been avoided if he would have accessed the health facilities at the CMCH.

8.1. CONCLUSION

The crude prevalence of diabetes is 6.5% in the select villages of Tirukalukundram block of Kanchipuram district, Tamil Nadu. This prevalence corroborates with the state rural prevalence of diabetes. The socio-economic context of the study sample revealed that the Scheduled caste is proportionately high among the landless labourers. There is significant variation between BCs as none of them have any land. All involved in small/petty businesses like utensil selling, tailoring, chicken shop, cycle repair shop and so on. It is noteworthy that around 30% of Most Backward caste the majority Naickers holding up to 2 acres of land. The small and middle peasants are belonging to lesser proportion of BCs and larger proportion of OCs whereas the majority (39%) of the BCs or their family members hold the government jobs or retired or professional jobs like Engineers. It is observed that none of the female members holding government job. Very few female family members are the professionals like software engineers.

Having this broader understanding on the socio-economic position, the treatment seeking revealed that the increasing expenses of the treatment in the private health care services made people to move from private to public / NGO or combine with public or NGO. There is also significant variation in experiencing symptoms across gender, caste and class. It is not only the experiencing symptoms but also in the treatment seeking. The quantitative survey has shown that there is no significant variation in the presence of complications and co-morbid condition across caste class and gender except the gender variation in the presence of cardiac problem, foot ulcer, TB, thyroid problem and stroke.

Similarly, there was gender differences observed in how the participants have perceived their onset of diabetes. The understanding of diabetes in terms of symptoms, causes, diagnosis and treatment has shown the congruence between the patients and other systems of medicine such as homeopathy, siddha. Similarly, the understanding of treatment among the patients is congruent with the allopathy practitioners. The everyday management has given a very clear and contrast pattern among the landless labourers, marginal farmers and people who are at home only. The determinants of everyday coping include the socio-economic condition, source of livelihood, income, priorities in life, routine and so on.

Despite plural availability of treatment, the individual interaction with health care services could be captured carefully where it is available. Who can access it, which is affordable, who can afford for what through the process of coping. The coping is a continuum from the

perception and experience of symptoms to treatment of patients in different health care services. As shown in earlier study in Chennai, the diet is only translated into food. Consumption of three meals per day itself is a big deal for most of the landless labourers but a balanced diet is maintained at the household where the class V participants are living.

As Tamil Nadu has pioneered in implementing health care services achieving good health status, it also created the NCD cell in the PHCs and GH in a phased manner through Tamil Nadu Health System Project funded by World Bank. It has piloted several model projects for the prevention and control of diabetes and other NCDs like hypertension, cancer and cardiovascular diseases. This project was initiated and piloted from 2008 to 2010 in Virudhunagar and Sivaganga district. The intervention strategies focused on not only opportunistic screening but also conducted several awareness programmes among different target groups such as adolescent groups in schools, Industrial work place, Pregnant mothers for gestational diabetes and opportunistic screening of people whoever visits the government health facility like PHC/ CHC/GH. Once the pilot got over in 2010, the project is taken further in other districts in a phased manner.

A separate NCD staff Nurse is appointed (on contract basis) and trained to handle the 'NCD corner' in the PHC and GH. These NCD cells are coordinated by the NCD cell in the district and the State Health Society. Hence the implementation is happening as per the plan. But as per the plan the screening of complications needed to be conducted there in the PHC. Apart from opportunistic screening and the provision of medicines for diabetes, the activities are seemed to be fragmented and needed to be compiled in order to prevent and control diabetes and other complications. As mentioned in the earlier section, the complications were handled through the chief minister health insurance but with the OOPE which made people to fall into BPL category.

In case of NCDs, over emphasis was on individual's life style instead of focusing on the larger social context which pointed to the working conditions, social pressures and nutritional status that lead to the onset of NCDs (Qadeer I, 1989). Now also the opportunistic screening translates the same meaning (only the individuals are focused). Hence at the subjective level, individuals with the symptoms whoever visit the health centre will have to be taken care in screening and diagnosis.

If the primary health care is planned and provided as per the Alma Atta declaration, the primary Health Centre has to deal with the preventive, promotive and curative care of diabetes

so that prevent the occurrence of complications and regular monitoring of the condition would happen. The accessibility issues such as transport, financial access, physical access is handled, then monitoring of the condition would also be handled.

The national health policy pointed out the decentralisation of planning as per the burden of diseases estimated recently as part of state level disease burden report (2016) might take care of the issues at that level. With enough funds, appropriate human health resources, health technology and planning would happen. The provision of drugs to the elder adults, monitoring of blood glucose at the sub centre level would help them the better access of treatment. It can be interpreted that the bio-chemical, experiential aspects are dealt with the primary health care system. An important area that is not adequately addressed is the psycho-social determinants in the daily management and coping with a chronic disease.

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ANNEXURE

ANNEXURE I

Table 3.10: Class wise distribution of Co-morbid condition

Co-morbid Condition	SC	MBC	BCM	BC	OC	TOTAL
NIL	65(1.9%)	58(65.2%)	9(60.0%)	21(58.3%)	4(57.1)	157(6.2%)
BP	23(21.9%)	23(25.8%)	6(40%)	11(30.6%)	2(28.6)	65(25.8%)
THYRIOD	2(1.9%)	2(2.2%)	0(0.0%)	0(0.0%)	0(0.0%)	4(1.6%)
ASTHMA	2(1.9%)	2(2.2%)	0(0.0%)	1(2.8%)	0(0.0%)	5(2.0%)
OTHERS	6(5.7%)	2(2.2%)	0(0.0%)	1(2.8%)	0(0.0%)	5(2.0%)
TB	4(1.6%)	1(0.4%)	0(0.0%)	0(0.0%)	0(0.0%)	5(2.0%)
EANLA	1(1.0%)	0(0.0%)	0(0.0%)	0(0.0%)	0(0.0%)	5(2.0%)
BP&THYRIOD	0	1(1.1%)	0(0.0%)	1(2.8%)	1(14.3%)	3(1.2%)
BP&TB	2(1.9%)	0(0.0%)	0(0.0%)	1(2.8%)	0	3(1.2%)
TB	2(1.9%)	0(0.0%)	0(0.0%)	1(2.8%)	0(0.0%)	3(1.2%)
TOTAL	105	89	15	36	7	

Table 3.11: Class wise distribution of Co-morbid condition

Co-morbid Condition	Landless labourers	Marginal Farmers	Small Farmers and Middle Peasants	Govt. Employee /retired / professional	Total
NIL	85(62.0%)	28 (88.3%)	11 (61.1%)	33 (58.9%)	157 (62.3%)
HYPERTENSION	34(24.8%)	9(22.0%)	5(27.8%)	17(30.4%)	65(25.8%)
THYRIOD	2(1.8%)	0	1(5.6%)	1(1.8%)	1(1.6%)
ASTHMA	4(2.9%)	0	0	1(1.8%)	5(3.6%)
OTHERS	5(3.6%)	3(7.3%)	0	1(1.8%)	9(3.6%)
TB	3(2.2%)	1(2.4%)	0	1(1.8%)	5(2.0%)
CANCER	1(0.7%)	0	0	0	1(0.4%)
BP& THYRIOD	0	0	1(5.6%)	2(3.6%)	3(1.2%)
BP& TB	3(2.2%)	0	0	0	3(1.2%)
TOTAL	137(100%)	41(100%)	18(100%)	56(100%)	252(100%)

ANNEXURE II LIST OF SELECT (STUDY) VILLAGES

S.No	Name of the village
1	Gandhinagar
2	Karumarappakkam
3	Kamarajanagar
4	Naduvakarai
5	Kunnavakkam
6	Aminjakarai
7	Veerapuram
8	Periyakattupakkam
9	Suradimangalam
10	Mullikulathur
11	Edaiyathur
12	Irumbulicheri
13	Jamberi
14	Pattaraikalani & Anna nagar
15	Mettu Egai
16	Pakkam
17	Kollamedu
18	Pandur
19	Nerumber
20	Aandimadam (Indira nagar)
21	Echangaranai
22	Ammanampakkam A
23	Ammanampakkam B
24	Perumbedu A
25	Perumbedu B

ANNEXURE III

INFORMED CONSENT FORM

The objectives, advantages and disadvantages of the research in which I am expected to participate, for which I have to give information has been explained to me.

I _____ residing at _____ willingly, (under no pressure from the researcher) agree to take part in this research. My consent is explicitly not for disclosing any personal information. For disclosing any such personal information obtained from the investigations conducted, further consent should be obtained.

I have been informed that JNU and the researcher Ms. D. Arutselvi will take my prior consent for disclosing any such personal information obtained from the investigations conducted. The researcher also informed that a pseudo name will be given to each study participant in order to maintain the confidentiality and the same pseudo name will be used for the dissemination of this research findings and further academic activities for the fulfillment of her PhD research at the Centre of Social Medicine and Community Health, Jawaharlal Nehru University, New Delhi – 110067.

Signatures

Participant

Witness

Principle Investigator.

Date: _____

அறிவிக்கப்பட்ட ஒப்புதல் படிவம்

நான் பங்கேற்கபோகும் ஆராய்ச்சியின் நோக்கங்கள், பயன்கள் மற்றும் தீங்குகளும், நான் கொடுக்க வேண்டிய தகவல்கள் பற்றியும் எனக்கு விளக்கம் அளிக்கப்பட்டது.

இடத்தில் வசிக்கும்
ஆகிய நான் முழுமனதுடனும்
ஆராய்ச்சியாளரின் எந்தவிதமான வற்புறுத்தலும் இன்றி இந்த ஆராய்ச்சியில் பங்கு
பெற ஒப்புதல் அளிக்கிறேன். என்னுடைய ஒப்புதல் தெளிவாக எந்த சொந்த(தனி
நபர்) தகவல்களை வெளியிடுவதற்கும் அல்ல. அப்படி சொந்த தகவல்களை
வெளியிடுவதற்கு என்னிடமிருந்து மேலும் ஒப்புதல் பெற வேண்டும்.

இவ்வாய்விலிருந்து சேகரிக்கப்பட்ட சொந்த தகவல்களை வெளியிட வேண்டும்
எனில் ஜவஹர்லால் நேரு பல்கலைக்கழகம் மற்றும் ஆய்வாளர் டி.அருட்செல்வி
அவர்களால் அதற்கு முன்பு ஒப்புதல் பெறப்பட்டும் என்றும் தெரிவிக்கப்பட்டது.
இரகசியம் காப்பதற்காக ஆய்வில் பங்கு பெறுவோர் ஒவ்வொருவருக்கும் ஒரு
போலி பெயர் கொடுக்கப்படும் என்றும் தான் புது டில்லியில் உள்ள ஜவஹர்லால்
நேரு பல்கலைக்கழகம், சமூக மருத்துவம் மற்றும் சமுதாய சுகாதாரம்
மையத்தில் பி.எச்.டி ஆராய்ச்சி படிப்பு முடிப்பதற்காக இந்த ஆராய்ச்சியின்
முடிவுகளை வெளியிடுவதற்காகவும் மற்றும் கூடுதல் கல்வி சம்பந்தமான
செயற்பாடுகளுக்காகவும் அதே போலி பெயர்தான் பயன்படுத்தப்படும் என்றும்
தெரிவித்தார்.

கையெழுத்து(கள்)

பங்கேற்பாளர்

சாட்சியாளர்

முதன்மை ஆய்வாளர்

தேதி:- _____

Participant Information Sheet

1. Purpose of the Study

The important purpose is to study the social dimensions of coping with type II diabetes among people diagnosed with type II diabetes in the select villages of Kanchipuram district, Tamil Nadu.

2. Study Procedures

In this research you may have to spend 30 to 45 minutes for an initial survey and for the in-depth study (if required) 2 to 3 hours. You can give your interview in two to three slots according to your convenience. The investigator will ask you the questions about your socio-economic profile, treatment seeking and diagnosis of diabetes, current disease and treatment profile and treatment expenses (in survey). During in-depth interview (if required) questions will be asked on understanding of diabetes, every day coping with treatment, involvement of household members, social support in coping with diabetes and interaction with health care services in treating diabetes. You can give your own responses as you feel and experienced the actual situations. You are also requested to give true responses as there are no right or wrong in it. If you do not like answering to any questions, you can decline to answer. The health services

3. Risk of the Study

There is no risk involve in this study.

4. Benefits from the Study:

The research findings will be useful to understand the problems in coping with type II diabetes at different levels from a social perspective. This will bring in the social dimension in planning of the prevention and control programmes for diabetes at the state and national level. In addition, this study will add insights to the existing health programme for the people with diabetes by RUWSEC (a NGO which works in the study area) and further strengthen their programme in addressing the felt needs of the people affected with diabetes.

5. Complications:

There will not be any complications in the participation of this study.

6. Compensations:

There will not be any kind of monetary compensation to participate in this study.

7. Confidentiality:

The personal identity of the participant, survey form, recorded information of in-depth interviews will be kept confidential. Prior consent will be obtained from the participant for disclosing any such personal information. A pseudo name will be given to each study participant in order to maintain the confidentiality and the same pseudo name will be used for dissemination of research findings and further academic activities for the partial fulfilment of this PhD research at the Centre of Social Medicine and Community Health, School of Social Sciences, Jawaharlal Nehru University, New Delhi – 110067.

8. Rights of participants:

The study participant is allowed to ask any doubts/questions related to this research. If the participant does not like to participate in the study, the participant is allowed to withdraw from the study at any point of time.

9. Alternatives to participation in the study:

In case, any participant will withdraw their participation when the study is going on, similar kind (matched) of participant will be recruited into the study.

10. Any other: _

பங்கேற்பாளருக்கான தகவல் ஏடு

1. ஆய்வின் நோக்கம்

காஞ்சிபுர மாவட்டத்தில் தேர்ந்தெடுக்கப்பட்ட கிராமங்களில் நீரிழிவால் பாதிக்கப்பட்ட மக்களிடம் நீரிழிவு (சர்க்கரை) நோயை கையாளுதலின் சமூக பரிமாணங்கள் பற்றி ஆராய்வதே இந்த ஆய்வின் நோக்கம் ஆகும்.

2. ஆய்வின் செயல்முறை

இந்த ஆய்வில் தாங்கள் முதல் கட்ட ஆய்விற்கு (தகவல் சேகரிப்பு) 30 முதல் 45 நிமிடங்கள் வரையிலும் இரண்டாம் கட்ட (ஆழ்ந்த) ஆய்விற்கு 2 - 3 மணி நேரங்கள் செலவிட நேரிடும். இதில் இரண்டு அல்லது மூன்று பகுதிகளாகவும் தங்களின் வசதிக்கேற்ப பங்கு கொள்ளலாம். ஆய்வாளர் முதல் கட்ட ஆய்வில் தங்களிடம் சமூக பொருளாதார, சர்க்கரை நோய் கண்டறிதல் மற்றும் சிகிச்சை பெறுதல், தற்போதைய நோய் மற்றும் சிகிச்சை விபரங்கள், சிகிச்சைக்கான செலவுகள் பற்றிய கேள்விகள் கேட்பார். ஆழ்ந்த நேர்காணலின் போது (தேவையிருப்பின்) நீரிழிவின் புரிதல், ஒவ்வொரு நாளும் சிகிச்சையை கையாளுதல், குடும்ப உறுப்பினர்களின் ஈடுபாடு, நீரிழிவை கையாளுதலில் சமூக ஆதரவு மற்றும் நீரிழிவு சிகிச்சை பெறுதலில் சுகாதார சேவைகளின் தொடர்பு ஆகியவற்றை பற்றி கேள்விகள் கேட்கப்படும். அதற்கு தங்களுடைய சொந்த கருத்துக்கேற்ப பதிலளிக்கலாம். மேலும் தங்களின் உண்மையான பதில்களை அளியுங்கள் என்று தயவு கூர்ந்துகேட்டுக் கொள்ளப்படுகிறீர்கள், ஏனெனில் இதில் சரி அல்லது தவறான பதில்கள் என்று எதுவும் கிடையாது.

3. ஆய்வின் இடர்பாடுகள்(ஆபத்து): இந்த ஆய்வில் எந்த இடர்பாடுகளும் கிடையாது.

4. ஆய்வின் பயன்கள்: ஆய்வின் முடிவுகள் நீரிழிவை கையாளுதலில் வெவ்வேறு மட்டத்தில் உள்ள பிரச்சினைகளை சமூக கண்ணோட்டத்தில் புரிந்து கொள்ள பயன்படும். இது மேலும் தேசிய மற்றும் மாநில நீரிழிவு தடுப்பு மற்றும் கட்டுப்படுத்துதல் திட்டத்தின் திட்டமிடலில் சமூக பரிமாணங்களை உள் கொண்டு வரும். இதனுடன் இந்த ஆய்வு, நீரிழிவால் பாதிக்கப்பட்ட ஏற்கனவே ரூசக் நடத்தி வரும் சுகாதார திட்டத்திற்கு நுண்ணறிவை சேர்த்து மேலும் அவர்களின் உணர்ந்த தேவைகளை எடுத்துரைத்து திட்டத்திற்கு வலுசேர்க்கும்.

5. சிக்கல்கள்:

இந்த ஆய்வில் பங்கேற்பதால் எந்த சிக்கல்களும் இருக்காது.

6. பங்கேற்பாளர் இழப்பீடு:

தாங்கள் இந்த ஆய்வில் பங்கு பெறுவதற்கு எந்த ஒரு ஊக்கத்தொகையும் தரப்படமாட்டாது.

7. இரகசியம்காத்தல்:

பங்கேற்பாளரின் சொந்த அடையாளம், தகவல் சேகரிக்கப்பட்ட படிவம், ஒலிநாடாவில் பதிவாக்கப்பட்ட ஆழ்ந்த நேர்காணல்கள் இரகசியமாக வைக்கப்படும். எந்த சொந்த தகவல்களை வெளியிட வேண்டும் எனில் அதற்கு முன்பு ஒப்புதல் பெறப்படும். இரகசியம் காப்பதற்காக ஆய்வில் பங்கு பெறுவோர் ஒவ்வொருவருக்கும் ஒரு போலி பெயர் கொடுக்கப்படும் என்றும் தான் புது டில்லியில் உள்ள ஜவஹர்லால் நேரு பல்கலைக்கழகம், சமூக மருத்துவம் மற்றும் சமுதாய சுகாதாரம் மையத்தில் பி.எச்.டி ஆராய்ச்சி படிப்பு முடிப்பதற்காக இந்த ஆராய்ச்சியின் முடிவுகளை வெளியிடுவதற்காகவும் மற்றும் கூடுதல் கல்வி சம்பந்தமான செயற்பாடுகளுக்காகவும் அதே போலி பெயர்தான் பயன்படுத்தப்படும்.

8. பங்கேற்பாளரின் உரிமைகள்:

இந்த ஆய்வுக்கு சம்மந்தப்பட்ட எந்த சந்தேகங்களையும்/கேள்விகளையும் தாங்கள் கேட்க அனுமதிக்கப்படுவீர்கள். தாங்கள் விருப்பப்படாவிட்டால், இந்த ஆய்விலிருந்து எந்த நேரத்திலும் விலகிக் கொள்ளலாம்.

9. ஆய்வில் பங்கேற்பதற்கான மாற்றுவழி:

ஒரு வேளை எந்த ஒரு பங்கேற்பாளராவது ஆய்வு நடந்து கொண்டிருக்கும் போது விலகிக்கொண்டால் அதேமாதிரியான (பொருத்தமுள்ள) ஒருவரை ஆய்வில் சேர்த்து கொள்ளப்படுவர்.

10. மற்றவை: எதுவுமில்லை

ANNEXURE IV

INFORMED CONSENT FORM (Health Care Providers)

The objectives, advantages and disadvantages of the research in which I am expected to participate, for which I have to give information has been explained to me.

I _____ residing at _____ willingly, (under no pressure from the researcher) agree to take part in this research. My consent is explicitly not for disclosing any personal information. For disclosing any such personal information (name, clinic/hospital name) obtained from the investigations conducted, further consent should be obtained.

I have been informed that JNU and the researcher Ms. D. Arutselvi will take my prior consent for disclosing any such personal information obtained from the investigations conducted. The researcher also informed that a pseudo name will be given to each study participant in order to maintain the confidentiality and the same pseudo name will be used for the dissemination of this research findings and further academic activities for the fulfillment of her PhD research at the Centre of Social Medicine and Community Health, Jawaharlal Nehru University, New Delhi – 110067.

Signatures

Participant

Witness

Principle Investigator.

Date: _____

அறிவிக்கப்பட்ட ஒப்புதல் படிவம் (Health Care Providers)

நான் பங்கேற்கபோகும் ஆராய்ச்சியின் நோக்கங்கள், பயன்கள் மற்றும் தீங்குகளும், நான் கொடுக்க வேண்டிய தகவல்கள் பற்றியும் எனக்கு விளக்கம் அளிக்கப்பட்டது.

இடத்தில் வசிக்கும்
ஆகிய நான் முழுமனதுடனும்
ஆராய்ச்சியாளரின் எந்தவிதமான வற்புறுத்தலும் இன்றி இந்த ஆராய்ச்சியில் பங்கு
பெற ஒப்புதல் அளிக்கிறேன். என்னுடைய ஒப்புதல் தெளிவாக எந்த சொந்த(தனி
நபர்) தகவல்களை வெளியிடுவதற்கும் அல்ல. அப்படி சொந்த தகவல்களை(பெயர்,
க்ளினிக் / மருத்துவமனையின் பெயர்) வெளியிடுவதற்கு என்னிடமிருந்து மேலும்
ஒப்புதல் பெற வேண்டும்.

இவ்வாய்விலிருந்து சேகரிக்கப்பட்ட சொந்த தகவல்களை வெளியிட வேண்டும்
எனில் ஜவஹர்லால் நேரு பல்கலைக்கழகம் மற்றும் ஆய்வாளர் டி.அருட்செல்வி
அவர்களால் அதற்கு முன்பு ஒப்புதல் பெறப்பட்டும் என்றும் தெரிவிக்கப்பட்டது.
இரகசியம் காப்பதற்காக ஆய்வில் பங்கு பெறுவோர் ஒவ்வொருவருக்கும் ஒரு
போலி பெயர் கொடுக்கப்படும் என்றும் தான் புது டில்லியில் உள்ள ஜவஹர்லால்
நேரு பல்கலைக்கழகம், சமூக மருத்துவம் மற்றும் சமுதாய சுகாதாரம்
மையத்தில் பி.எச்.டி ஆராய்ச்சி படிப்பு முடிப்பதற்காக இந்த ஆராய்ச்சியின்
முடிவுகளை வெளியிடுவதற்காகவும் மற்றும் கூடுதல் கல்வி சம்பந்தமான
செயற்பாடுகளுக்காகவும் அதே போலி பெயர்தான் பயன்படுத்தப்படும் என்றும்
தெரிவித்தார்.

கையெழுத்து(கள்)

பங்கேற்பாளர்

சாட்சியாளர்

முதன்மை ஆய்வாளர்

தேதி:- _____

Participant Information Sheet (Health Care Providers)

1. Purpose of the Study

The important purpose is to study the social dimensions of coping with type II diabetes among people diagnosed with type II diabetes in the select villages of Kanchipuram district, Tamil Nadu.

2. Study Procedures

In this research you may have to spend 45 minutes to 1 hour for this in-depth study. You can give your interview in two to three slots according to your convenience. The investigator will ask you the questions about your understanding of diabetes, experiences in providing diabetes care and also problems / constraints faced by you in your practice related to diabetes. You are requested to give responses as you feel and experienced the actual situations. If you do not like to answer any questions, you can decline to answer.

3. Risk of the Study

There is no risk involve in this study.

4. Benefits from the Study:

The research findings will be useful to understand the problems in coping with type II diabetes at different levels from a social perspective. This will bring in the social dimension in planning of the prevention and control programmes for diabetes at the state and national level. In addition, this study will add insights to the existing health programme for the people with diabetes by RUWSEC (a NGO which works in the study area) and further strengthen their programme in addressing the felt needs of the people affected with diabetes.

5. Complications:

There will not be any complications in the participation of this study.

6. Compensations:

There will not be any kind of monetary compensation to participate in this study.

7. Confidentiality:

The personal identity of the participant, survey form, recorded information of in-depth interviews will be kept confidential. Prior consent will be obtained from the participant for disclosing any such personal information. A pseudo name will be given to each study participant in order to maintain the

confidentiality and the same pseudo name will be used for dissemination of research findings and further academic activities for the partial fulfillment of this PhD research at the Centre of Social Medicine and Community Health, School of Social Sciences, Jawaharlal Nehru University, New Delhi – 110067.

8. Rights of participants:

The study participant is allowed to ask any doubts/questions related to this research. If the participant do not like to participate in the study, the participant is allowed to withdraw from the study at any point of time.

9. Any other: _

பங்கேற்பாளருக்கான தகவல் ஏடு (Health Care Providers)

1. ஆய்வின் நோக்கம்

காஞ்சிபுர மாவட்டத்தில் தேர்ந்தெடுக்கப்பட்ட கிராமங்களில் நீரிழிவால் பாதிக்கப்பட்ட மக்களிடம் நீரிழிவு (சர்க்கரை) நோயை கையாளுதலின் சமூக பரிமாணங்கள் பற்றி ஆராய்வதே இந்த ஆய்வின் நோக்கம் ஆகும்.

2. ஆய்வின் செயல்முறை

இந்த ஆய்வில் தாங்கள் முதல் கட்ட ஆய்விற்கு (தகவல் சேகரிப்பு) 30 முதல் 45 நிமிடங்கள் வரையிலும் இரண்டாம் கட்ட (ஆழ்ந்த) ஆய்விற்கு 2 - 3 மணி நேரங்கள் செலவிட நேரிடும். இதில் இரண்டு அல்லது மூன்று பகுதிகளாகவும் தங்களின் வசதிக்கேற்ப பங்கு கொள்ளலாம். ஆய்வாளர் முதல் கட்ட ஆய்வில் தங்களிடம் சமூக பொருளாதார, சர்க்கரை நோய் கண்டறிதல் மற்றும் சிகிச்சை பெறுதல், தற்போதைய நோய் மற்றும் சிகிச்சை விபரங்கள், சிகிச்சைக்கான செலவுகள் பற்றிய கேள்விகள் கேட்பார். ஆழ்ந்த நேர்காணலின் போது (தேவையிருப்பின்) நீரிழிவின் புரிதல், ஒவ்வொரு நாளும் சிகிச்சையை கையாளுதல், குடும்ப உறுப்பினர்களின் ஈடுபாடு, நீரிழிவை கையாளுதலில் சமூக ஆதரவு மற்றும் நீரிழிவு சிகிச்சை பெறுதலில் சுகாதார சேவைகளின் தொடர்பு ஆகியவற்றை பற்றி கேள்விகள் கேட்கப்படும். அதற்கு தங்களுடைய சொந்த கருத்துக்கேற்ப பதிலளிக்கலாம். மேலும் தங்களின் உண்மையான பதில்களை அளியுங்கள் என்று தயவு கூர்ந்துகேட்டுக் கொள்ளப்படுகிறீர்கள், ஏனெனில் இதில் சரி அல்லது தவறான பதில்கள் என்று எதுவும் கிடையாது.

3. ஆய்வின் இடர்பாடுகள்(ஆபத்து): இந்த ஆய்வில் எந்த இடர்பாடுகளும் கிடையாது.

4. ஆய்வின் பயன்கள்: ஆய்வின் முடிவுகள் நீரிழிவை கையாளுதலில் வெவ்வேறு மட்டத்தில் உள்ள பிரச்சினைகளை சமூக கண்ணோட்டத்தில் புரிந்து கொள்ள பயன்படும். இது மேலும் தேசிய மற்றும் மாநில நீரிழிவு தடுப்பு மற்றும் கட்டுப்படுத்துதல் திட்டத்தின் திட்டமிடலில் சமூக பரிமாணங்களை உள் கொண்டு வரும். இதனுடன் இந்த ஆய்வு, நீரிழிவால் பாதிக்கப்பட்ட ஏற்கனவே ரூசக் நடத்தி வரும் சுகாதார திட்டத்திற்கு நுண்ணறிவை சேர்த்து மேலும் அவர்களின் உணர்ந்த தேவைகளை எடுத்துரைத்து திட்டத்திற்கு வலுசேர்க்கும்.

5. சிக்கல்கள்:

இந்த ஆய்வில் பங்கேற்பதால் எந்த சிக்கல்களும் இருக்காது.

6. பங்கேற்பாளர் இழப்பீடு:

தாங்கள் இந்த ஆய்வில் பங்கு பெறுவதற்கு எந்த ஒரு ஊக்கத்தொகையும் தரப்படமாட்டாது.

7. இரகசியம்காத்தல்:

பங்கேற்பாளரின் சொந்த அடையாளம், தகவல் சேகரிக்கப்பட்ட படிவம், ஒலிநாடாவில் பதிவாக்கப்பட்ட ஆழ்ந்த நேர்காணல்கள் இரகசியமாக வைக்கப்படும். எந்த சொந்த தகவல்களை வெளியிட வேண்டும் எனில் அதற்கு முன்பு ஒப்புதல் பெறப்படும். இரகசியம் காப்பதற்காக ஆய்வில் பங்கு பெறுவோர் ஒவ்வொருவருக்கும் ஒரு போலி பெயர் கொடுக்கப்படும் என்றும் தான் புது டில்லியில் உள்ள ஜவஹர்லால் நேரு பல்கலைக்கழகம், சமூக மருத்துவம் மற்றும் சமுதாய சுகாதாரம் மையத்தில் பி.எச்.டி ஆராய்ச்சி படிப்பு முடிப்பதற்காக இந்த ஆராய்ச்சியின் முடிவுகளை வெளியிடுவதற்காகவும் மற்றும் கூடுதல் கல்வி சம்பந்தமான செயற்பாடுகளுக்காகவும் அதே போலி பெயர்தான் பயன்படுத்தப்படும்.

8. பங்கேற்பாளரின் உரிமைகள்:

இந்த ஆய்வுக்கு சம்மந்தப்பட்ட எந்த சந்தேகங்களையும்/கேள்விகளையும் தாங்கள் கேட்க அனுமதிக்கப்படுவீர்கள். தாங்கள் விருப்பப்படாவிட்டால், இந்த ஆய்விலிருந்து எந்த நேரத்திலும் விலகிக் கொள்ளலாம்.

10. மற்றவை: எதுவுமில்லை

ANNEXURE V

Interview Schedule

Socio-demographic profile:

Name/Address:

Age:

Sex:

Education:

Occupation and Land owning details:

Income:

Caste and Religion:

House details: Katcha/ Pucca

Rented/ Own: rent

Other members in the family:

S.No	Name	Relationship	Age	Occupation	Income

No. of dependents in the family:

Current Disease and Treatment Profile:

Age at onset:

Duration:

Complication due to diabetes: weakness / tiredness

Co-morbidity:

Biochemical profile (if records are available):

Fasting/PP: HbA1c:

Drug details: Metformin / Glibenclamide / B.complex / Calcium with D3

Presence of other family member with diabetes: Father had diabetes/had kidney problem

HISTORY OF DIABETES

1. What were the symptoms experienced by you before the diagnosis of diabetes?

2. Prior to diagnosis, what were the symptoms you worried for and felt that you were having some health problem?

3. At what stage of symptoms (severity) did you feel that you should do something about it or tried to visit a health care facility?

II.HISTORY OF TREATMENT SEEKING and CURRENT TREATMENT

4. Whom were the different practitioners (formal and informal; across systems of medicine) you visited for diagnosis of diabetes and then treatment? Describe in detail as much as you are able to recall...

Doctor	Complaints	Investigation & diagnosis	Treatment /advice

5. Do you aware about the long term effects of diabetes? If yes, what are they?

6. Did you receive any advice to go for other investigations other than blood glucose test?If yes, what are they?

7. How much do you spend for your treatment, please provide the details?

No. of OP visits / year: _____		IP visit if any /year	
Expenses in Rupees (Rs) for last OP visit		Health problem:	Health problem:
		Visit 1 (cost in Rs)	Visit 2 (cost in Rs)
Doctor/ ward			
Medicine			
Investigation			
Transport			
Food (if spent)			
Loss of days			
Loss of wage/ day			

Source of payment:

Interview Schedule

நீரிழிவு (சர்க்கரை) நோயை கையாளுதலின் சமூக பரிமானங்கள்: தமிழ்நாட்டின் காஞ்சிபுர மாவட்டத்தில் தேர்ந்தெடுக்கப்பட்ட கிராமங்களில் ஆய்வு.

சமூக மக்களியல் தகவல்கள் (Socio – demographic details)

பெயர் / முகவரி:

வயது:

பாலினம்:

கல்வி:

வருமானம்:

தொழில் மற்றும் நில உரிமை விவரம்:

ஜாதி மற்றும் மதம்:

குடும்பத்தின் வகை:

வீட்டின்வகை: கச்சா/பக்கா

மற்ற குடும்ப நபர்களின் விபரம்:

வ. எண்	பெயர்	உறவுமுறை	வயது	தொழில்	வருமானம்

குடும்பத்தில் சிறியவர்கள் / வயதானவர்களின் எண்ணிக்கை:

தற்போதைய நோய் (நீரிழிவு) மற்றும் சிகிச்சை பற்றிய தகவல்கள்

நீரிழிவு நோய் ஏற்பட்ட வயது:

காலம் (மொத்த வருடங்கள்) :

நீரிழிவால் ஏற்பட்ட மற்ற உடல் சிக்கல்கள் :

மற்ற நோய்கள் :

உயிர்வேதி (Bio – Chemical) தகவல்கள் - (மருத்துவ ஆவணம் இருப்பின்)

சாப்பிடும் முன்/ பின் இரத்த சர்க்கரை அளவு /தேதி:

Hb1c அளவு /தேதி :

உட்கொள்ளும் மருந்துகளின் விவரம்:

மற்ற குடும்ப நபருக்கு நீரிழிவு இருப்பின் அவர்/ அவர்களுடைய விவரம்.

நீரிழிவு தாக்குதலின் வரலாறு

1. தங்களுக்கு நீரிழிவு நோய் என்று அறிவதற்கு முன் என்னென்ன அறிகுறிகள் இருந்தன?
2. நீரிழிவை கண்டறிவதற்கு முன் எந்த அறி குறிகளுக்காக தாங்கள் மிகவும் வருத்த மடைந்து தனக்கு உடல் சுகமில்லை என்று உணர்ந்தீர்களா?
3. அறிகுறிகளின் எந்த நிலையில் (அதிகமாக காணும் நிலை) நீங்கள் ஏதாவது செய்ய வேண்டும் என்றோ அல்லது சுகதார நிலயத்துக்கோ (மருதுவமனைக்கோ) செல்ல வேண்டும் என்று நினைத்தீர்கள்?

சிகிச்சை எடுத்துக் கொண்ட வரலாறு மற்றும் தற்போதைய சிகிச்சை

4. உங்கள் நினைவுக்கு எட்டியவரையில் நீங்கள் எந்தெந்த மருத்துவரிடம் (வைத்தியரிடம்) உங்கள் நிலையை அறிய மற்றும் சிகிச்சைப் பெற சென்றீர்கள் என்று விரிவாக சொல்ல முடியுமா?

வ. எண்	வருடம்	தொந்தரவுகள் (அறிகுறிகள்)	மருத்துவர்	ஆய்வுகள் மற்றும் நோய்நிலை கண்டறிதல்	சிகிச்சை

5. நீரிழிவு நோயின் நீண்டகால விளைவுகள் பற்றி உங்களுக்கு தெரியுமா? ஆம் எனில் என்னென்ன?

6. நீங்கள் இரத்த சர்க்கரை அல்லாத மற்ற ஏதேனும் பரிசோதனை செய்யும்படி அறிவுரை பெற்றீர்களா? ஆம் எனில் என்னென்ன பரிசோதனைகள்?

7. சிகிச்சைக்கான செலவுகள்

புறநோயாளியாக மருத்துவரை சந்தித்தது/ ஒருவருடத்தில்:____முறை		உட்புறநோயாளியாக மருத்துவமனையில் இருந்தது /கடந்தவருடத்தில்	
கடைசி மருத்துவர் சந்திப்பு - செலவுகள் ரூபாயில் (Rs)		உடல் நலப்பிரச்சனை:	உடல் நலப்பிரச்சனை:
		Visit 1 (செலவுகள் ரூபாயில் (Rs))	Visit 2 (செலவுகள் ரூபாயில் (Rs))
மருத்துவர்/ உள்ளிருப்பு சிகிச்சயளித்தல்			
மருந்து			
பரிசோதனைகள்			
பயணம்			
உணவு			
வேலை இழந்த நாட்கள்			
வருமான இழப்பு/ஒரு நாள்			

செலவிற்கான முக்கிய ஆதாரம்:

ANNEXURE VI

Interview guide – Patients with type II diabetes

Understanding of diabetes

What are the important symptoms of diabetes?

What causes diabetes?

What is an Ideal blood sugar?

From your point of view, can you describe the effective diabetes management?

What affects blood sugar?

What are the complications of diabetes?

What worries you about diabetes?

Experiencing and coping with diabetes at the Individual level and the household level

Can you describe your daily routine from waking in the morning to when you go to bed?

- a) Role as a care taker
- b) Household work
- c) Work outside the home

Is there any difference between a Sunday and a weekday? Is there any time during the day on a weekday and/or weekend when you have more free time? What do you typically do with that time? (leisure)

Can you tell me about how you care for diabetes every day?

- a) Medication

- b) Food intake
- c) Rest
- d) Exercise

What advice have you received from your health care provider regarding all of the above?

What are the aspects of treatment advice you are able to follow and what are the aspects you are not able to follow?

Probe: If some treatment advice could not be followed, what is the reason?

What is biggest challenge that you are facing which affects the effective management of diabetes? / to put in other words what you need to manage your diabetes effectively?

Do you have the habit of fasting? If so, Kindly give the details of how you take food as well drugs during fasting days?

Has diabetes changed your daily routine? If you have seen a change in your life due to diabetes, can you explain the ways in which your daily life has changed?

Has diabetes altered or changed your life in any way? If yes, is it more in any particular area of your life, such as work, family life, marriage, sexual relationships, social relationships and so on?

Have you ever felt stress or tension in relation to diabetes?

Do you feel insecure about life because of diabetes?

Was anyone available to help you when you first found out that you had diabetes?

How have family members / relatives/ people at work reacted to your having diabetes? Have you ever felt discriminated?

Are your family members are aware of your illness and treatment? Do they actively participate and support you treatment? Who are the family members who actually support you?

Do they understand the seriousness of the illness?

Have you ever attend the separate education or counselling session on managing diabetes? If so, please provide the details.

Whether any of the family members ever visited the doctor/ health care professional/ education or counselling session with you?

Do you feel that adequate concern is shown by your family members?

Whether anyone in the family helps you to take care of your everyday needs of diabetes?

Who makes decision about your diabetes care?

Probes: where to go for treatment? What kind of treatment? How much can be spent for your treatment?

How do you meet the expenses for diabetes treatment regularly?

Do you know someone else who is also diabetic? If so, do you discuss about your illness with them?

Do you feel relaxed when you share about your illness to someone?

In case if the study participant is woman, Is someone in your house affected with diabetes? (in- laws, husband) if so, in what way they are being cared for diabetes? Do you feel that there is a difference of their diabetes treatment from yours'? if yes, can you explain?

If you would fall ill, what would you do? Who among family or others usually takes care of you?

Do you ask for any help for your work at home or work place?

Do you feel bad about that you are dependent because of diabetes?

Interaction with health care services

Can you describe your OP visit to your regular health care service?

Probes:

How do you go there?

Who are the health staff you visit there?

How long you will have to wait to see a doctor / any other health staff?

How much time does the doctor spend with you?

Have you been informed about the effects and side effects of the medicines you are taking?

Have you been told about the complications of diabetes?

Did you ever receive advice to do tests for any complications?

Are you satisfied with the treatment you receive?

Probes: do you get your doubts clarified with the doctor?

What kind of questions do you ask to your health care provider?

How the doctor respond you?

Did you ever seek cure for diabetes?

What are the problems / constraints you faced during your OP visit/ IP visit?

If treatment is accessed from different system, have you informed the practitioner/ healer that you are taking medicines from different sources?

Example: may be some home remedies / herbal medicines from a local healer / medicines from Ayurveda/siddha/other system

Interview Guide – Patients with type II diabetes

நீரிழிவு நோய் பற்றிய புரிதல்

நீரிழிவு (சர்க்கரை) நோயின் அறிகுறிகள் என்னென்ன?

நீரிழிவு நோய் ஏற்பட காரணம் என்ன?

சீரான (சரியான) இரத்தத்தின் சர்க்கரை அளவு என்ன?

உங்கள் கண்ணோட்டத்தில், பயனளிக்கக்கூடிய நீரிழிவு கையாளுதல்

(மேலாண்மை) பற்றி விவரிக்க முடியுமா?

இரத்தத்தின் சர்க்கரையை எதுபாதிக்கும்?

நீரிழிவு சிக்கல்கள் (கோளாறுகள்), என்னென்ன?

நீரிழிவு பற்றி உங்களை வருந்த வைப்பது என்ன?

தனிநபர் மற்றும் குடும்ப அளவிலான நீரிழிவு நோயின் அனுபவம் மற்றும் கையாளுதல்

காலையில் எழுந்ததிலிருந்து இரவு தூங்கும் வரை உங்களின் அன்றாட (வழக்கம்) நடைமுறைகளை விவரிக்க முடியுமா?

அ) குடும்ப பாதுகாவலராக

ஆ) வீட்டுவேலைகள்

இ) வீட்டுக்கு வெளியில் உள்ள வேலைகள்.

ஞாயிற்றுக்கிழமைக்கும் மற்ற நாளுக்கும் ஏதாவது வித்தியாசம் இருக்கிறதா? வார கடைசியில் / ஏதாவது ஒருநாளில் மிகுந்த வேலையில்லாத (சும்மா) நேரம் இருக்கிறதா? அந்த நேரத்தில் என்ன செய்வீர்கள்?

ஒவ்வொரு நாளும் சர்க்கரை நோயை எப்படி பார்த்துக் கொள்வீர்கள் என்று சொல்ல முடியுமா?

அ) மருந்து ஆ) உணவுஉட்கொள்வது இ) ஓய்வு ஈ) உடற்பயிற்சி

மேற்கூறிய அனைத்தைப் பற்றியும் உங்களின் மருத்துவர் / வைத்தியரிடம் (Health care provider) நீங்கள் பெற்ற அறிவுரைகள் என்னென்ன?

எந்தெந்த சிகிச்சை அறிவுரைகளை பின்பற்ற முடிகிறது மற்றும் எவற்றை பின்பற்ற முடியவில்லை?

சில சிகிச்சை அறிவுரைகளை பின்பற்ற முடியவில்லை என்றால், அதற்கு காரணம் என்ன?

பயனளிக்கக்கூடிய (ஆற்றல்மிக்க) நீரிழிவு கையாளுதலை பாதிக்கும் நீங்கள் எதிர் கொள்ளும் மிகப்பெரிய சவால் என்ன? நீரிழிவை சரியான முறையில் கையாளுவதற்கு உங்களின் தேவை என்ன?

உங்களுக்குவிரதம் இருக்கும்பழக்கம் இருக்கிறதா? இருப்பின் விரதநாட்களில் உணவு மற்றும் மருந்துகளை எப்படி எடுக்கிறீர்கள் என்ற தகவல்களை தயவுசெய்து கொடுங்கள்.

நீரிழிவு நோய் தங்களின் அன்றாட நடைமுறைகளை மாற்றியிருக்கிறதா? நீங்கள் உங்கள் வாழ்க்கையில் நீரிழிவு நோயினால் மாற்றத்தை கண்டிருந்தால், உங்களுடைய அன்றாட வாழ்க்கை எந்த விதமாக மாறியிருக்கிறது என்று விளக்க முடியுமா?

நீரிழிவு தங்கள் வாழ்க்கையை ஏதாவது பெரிய விதமாக மாற்றியிருக்கிறதா? ஆம் எனில், ஏதாவது குறிப்பிடக்கூடிய வாழ்க்கை பகுதியில் (area)வேலை (தொழில்), குடும்ப வாழ்க்கை, திருமணம், தாம்பத்திய உறவுமுறை, சமூக உறவு முறை போன்றவை? மற்றும் பல.

நீரிழிவு சம்பந்தமாக நீங்கள் மனஇறுக்கம் / அழுத்தத்தை உணர்ந்தீர்களா?

நீரிழிவினால் வாழ்க்கைக்கு உத்திரவாதமில்லை என்று உணர்கிறீர்களா?

முதன்முதலில் உங்களுக்கு நீரிழிவு என்று அறிந்த போது உங்களுக்கு உதவுவதற்கு யாரேனும் இருந்தார்களா?

உங்களுக்கு நீரிழிவுநோய் இருப்பதற்கு குடும்பநபர்கள்/ உறவினர்கள், வேலை பார்க்கும் இடத்தில் உள்ளவர்கள் எப்படி நடந்து கொண்டார்கள்?

உங்களுடைய குடும்பநபர்களுக்கு உங்களின் உடல்நலக்குறைவு மற்றும் சிகிச்சை பற்றி தெரியுமா? உங்களின் சிகிச்சையில் தீவிரமாக பங்கெடுத்தும் மற்றும் ஆதரவாகவும் இருப்பவர்கள் யார்? குடும்ப உறுப்பினர்களில் உண்மையில் உதவியாக இருப்பவர் யார்?

நோயின் தீவிரத்தை பற்றி புரிந்து கொள்கிறார்களா?

உங்களின் நீரிழிவு கவனிப்பது (care) பற்றி முடிவு எடுப்பது யார்? ஆய்வுக்குறிப்புகள்;

சிகிச்சைக்கு எங்கு செல்ல வேண்டும்? எவ்வளவு செலவு செய்ய வேண்டும்?

வழக்கமாக நீரிழிவு சிகிச்சைக்கான செலவுகளை எப்படி சந்திக்கிறீர்கள்?

நீரிழிவு உள்ள மற்றொருவரை உங்களுக்கு தெரியுமா? அப்படியானால், நீங்கள் உங்களின் நோயை பற்றி கலந்தாலோசனை செய்வீர்களா?

உங்களுடைய நோயை பற்றி மற்றவருடன் பகிர்ந்து கொள்ளும் போது நிம்மதியை உணர்கிறீர்களா?

உங்களுக்கு உடல்நிலை சரியில்லாமல் போனால் என்ன செய்வீர்கள்? வழக்கமாக யார் (குடும்ப நபர் / மற்றவர்கள்) உங்களை பார்த்துக் கொள்வார்கள்?

உங்கள் வேலைக்காக குடும்பத்திலோ / வேலைபார்க்கும் இடத்திலோ உதவி கேட்பீர்களா?

நீரிழிவினால் நீங்கள் மற்றவரை சார்ந்திருக்க வேண்டியிருப்பதை கெட்டது என்று நினைக்கிறீர்களா?

உங்களுடைய சுகாதார சேவையில் வழக்கமான வெளிப்புற நோயளி சந்திப்பு பற்றி விவரிக்க முடியுமா?

Probes:

அங்கு எப்படி செல்வீர்கள்?

எந்தெந்த சுகாதார ஊழியர்களைச் சந்திப்பீர்கள்?

மருத்துவரை அல்லது மற்ற சுகாதார ஊழியரை பார்க்க எவ்வளவு நேரம் நீங்கள் காத்திருக்க வேண்டும்?

தங்களுடன் மருத்துவர் எவ்வளவு நேரம் செலவிடுவார்?

நீங்கள் எடுக்கும் மருந்துகளின் விளைவுகள் மற்றும் பக்கவிளைவுகள் பற்றி தெரிவிக்கப்பட்டதா?

நீரிழிவினால் ஏற்படும் சிக்கல்கள் பற்றி உங்களுக்கு சொல்லப் பட்டிருக்கிறதா?

எந்த சிக்கல்களுக்காவது பரிசோதனை செய்யும்படி அறிவுறுத்தப் பட்டிருக்கிறீர்களா?

நீங்கள் பெறும் சிகிச்சையில் உங்களுக்கு திருப்தி இருக்கிறதா?

உங்களுடைய சந்தேகங்களை மருத்துவரிடம் தெளிவு பெற்றிருக்கிறீர்களா?

சுகாதாரம் (சிகிச்சை) அளிப்பவரிடம் என்ன மாதிரியான கேள்விகளை கேட்பீர்கள்?

நீரிழிவை குணப்படுத்த எப்பொழுதாவது நாடியிருக்கிறீர்களா?

வெவ்வேறு மருத்துவ முறையிலிருந்து சிகிச்சை பெற்றிருந்தால், நீங்கள் அதை (வெவ்வேறு ஆரம்ப இடத்தில் மருந்து எடுப்பதை) மருத்துவரிடமோ/ வைத்தியரிடமோ தெரிவித்திருக்கிறீர்களா?

எடுத்துக்காட்டாக: வீட்டுவைத்தியமாக இருக்கலாம்/ மூலிகைமருந்து / நாட்டு வைத்தியரிடமிருந்து / ஆயுர்வேதமருந்து / சித்தா / மற்ற மருந்துமுறை.

ANNEXURE VII

Health Care Providers - Interview Guide

Name:

Address:

Profession:

Health Care Facility:

When did you start your practice in this area? month year

Since how many years are you practicing in this area _____years

Consultation fee per patient _____ (min) to _____ (max)

Timings of practice at this clinic _____

Approximate number of patients seen by you per day in your practice _____ to

Approximate number of diabetes patients seen by you per day in your practice ____ to

Understanding and treatment of Diabetes

Please tell me about your understanding of diabetes?

Probe: the principle of your system (discipline) may vary from other system (discipline) of medicine

What are the important symptoms of diabetes?

What causes diabetes?

What is an Ideal blood sugar?

What affects blood sugar?

What are the complications of diabetes?

What worries you about diabetes?

Do you see a lot of diabetic patients in your practice?

How long have you been working with diabetic patients?

From your experience, could you tell me how do you suspect diabetes in your practice/ in other words when do you ask for a blood sugar check up?

What from your experience is the best way to diagnose diabetes?

Can you describe how you treat a new diabetic patient?

In your point of view, can you describe the effective diabetes management?

Do you explain your patients about the effects and side effects of the drugs which are prescribed?

Once diabetes is diagnosed what are the various laboratory tests you prescribe to your patients?

What sorts of questions do patients come in with? Can you describe some of the more surprising questions you've been asked?

What are some of the factors which lead to poor compliance?

What are the problems faced by you in effective diabetes management of your patients?

What, if any, background information do you need about your patients in order to manage their diabetes successfully?

Probes: How, if at all, does the patient's culture, ethnic background or family affect management of this disease?

What, if anything, do you have to know about their families?

Follow up questions:

(a) Do you know the family members of your diabetic patients?

(b) Do you treat the family members of your diabetic patients?

How much time do you spend with a patient?

Have you ever asked a patient that whether they take any other medicines for diabetes other than your prescription?

As a practitioner, what will be your advice for a patient who is taking medicines from different systems of medicine? For example a combination of siddha and allopathy.. what are the probable consequences if a patient consuming both the medicines?

Do you refer patients to specialty clinics? If so, what kind of patients do you refer?

How do you update your knowledge?

What are the sources/people from where/whom you used to get information about new medicines for treating diabetes? For example.. Pharma (Medical representatives)

What are the problems / constraints faced by you in practice?

Is there anything that health care providers do which may contribute to poor compliance?

Health Care Providers – Interview Guide

பெயர்:

முகவரி:

தொழில்:

இந்த இடத்தில் எப்பொழுது உங்களின் மருத்துவ பயிற்சியை (தொழிலை - Practice) ஆரம்பித்தீர்கள்? _____ மாதம் _____ வருடம்.

எவ்வளவு வருடங்களாக இங்கு மருத்துவ தொழில் செய்து வருகிறீர்கள்?
ஒரு நோயாளிக்கு ஆலோசனைக் கட்டணம் ----- இருந்து ----- வரை.

இந்த மருத்துவ மையத்தில் உங்களின் ஆலோசனை நேரம் -----

ஒரு நாளில் எத்தனை நோயாளிகளை பார்ப்பீர்கள் ----- இருந்து ----- வரை.

ஒரு நாளில் எத்தனை நீரிழிவு நோயாளிகளை பார்ப்பீர்கள் ----- இருந்து -----
வரை.

நீரிழிவு பற்றி உங்களின் புரிதலை தயக்கூர்ந்து சொல்ல முடியுமா?

ஒரு மருத்துவ முறையினை மூலக் கோட்பாடும் மற்றொரு மருத்துவ முறை
மூலக் கோட்பாடும் வேறுபட்டு இருக்கலாம்.

நீரிழிவின் அறிகுறிகள் என்ன?

நீரிழிவு ஏற்பட காரணம் என்ன?

சீரான இரத்தத்தின் சர்க்கரை அளவு என்ன?

எது இரத்தத்தின் சர்க்கரையை பாதிக்கும்?

நீரிழிவின் சிக்கல்கள் என்னென்ன?

நீரிழிவு பற்றி உங்களை வருந்த வைப்பது என்ன?

உங்களின் பயிற்சியின் (தொழிலின்) போது நிறைய நீரிழிவு நோயாளிகளை பார்ப்பீர்களா?

எவ்வளவு காலமாக நீங்கள் நீரிழிவு நோயாளிகளுக்கிடையே வேலை செய்கிறீர்கள்?

உங்களுடைய அனுபவத்தில், நீரிழிவு என்று எப்படி சந்தேகிக்கீர்கள் / மற்ற வர்த்தகத்தில், எப்பொழுது இரத்த சர்க்கரை அளவை சோதனை செய்ய சொல்வீர்கள்?

புதிய நீரிழிவு நோயாளிக்கு எப்படி சிகிச்சை அளிப்பீர்கள் என்று விவரிக்க முடியுமா?

உங்களுடைய கண்ணோட்டத்தில் பயனளிக்கக்கூடிய (ஆற்றல் மிக்க) நீரிழிவு கையாளுதல் பற்றி விவரிக்க முடியுமா?

நீங்கள் உங்களுடைய நோயாளிகளுக்கு நீங்கள் கொடுக்கும் மருந்துகளின் விளைவுகள் மற்றும் பக்க விளைவுகள் பற்றி விளக்குவீர்களா?

நீரிழிவு நோய் என்று கண்டறிந்த உடன் என்னென்ன மருந்துவ பரிசோதனைகளை செய்ய பரிந்துரைப்பீர்கள்?

என்ன மாதிரியான கேள்விகளுடன் நோயாளிகள் வருவார்கள்? உங்களிடம் / கேட்பப்பட்ட மிகவும் ஆச்சரியப்படக்கூடிய கேள்விகள் சிலவற்றை விவரிக்க முடியுமா?

குறைபாடுடைய சிகிச்சை கீழ்படிதலுக்கு (poor compliance) வழிவகுக்கும் சில காரணிகள் என்ன?

உங்கள் நோயாளி பயனளிக்க கூடிய நீரிழிவு கையாளுதலில் நீங்கள் என்னென்ன பிரச்சனைகளை எதிர்கொள்கிறீர்கள்?

வெற்றிகரமாக நீரிழிவை கையாள உங்களுக்கு நோயாளி பற்றிய பின்னணி தகவல்கள் தேவைப் பட்டால் ... சிகிச்சையை முழுவதும் கடைபி்க்க முடியாமல் போவதற்கு.

நோயாளியின் அனைத்தும் பண்பாடு, இனத்தின் பின்னணி அல்லது குடும்பம் நோயைக் கையாளுதலை பாதித்தால்.

நீங்கள் அவர்களுடைய குடும்பத்தை பற்றி அறிய வேண்டியவை எதாவது இருந்தால்.

உங்களுக்கு நீரிழிவு நோயாளிகளின் குடும்ப உறுப்பினர்களை தெரியுமா?

நீங்கள் உங்களின் நீரிழிவு நோயாளிகளின் குடும்ப உறுப்பினர்களுக்கு சிகிச்சை அளிக்கிறீர்களா?

ஒரு நோயாளியுடன் எவ்வளவு நேரம் செலவிடுவீர்கள்?

நீங்கள் பரிந்துரை செய்த மருந்துகள் அல்லாத நீரிழிவுக்கு வேறு மருந்து எடுக்கிறார்களா என்று எப்பொழுதாவது கேட்டிருக்கிறீர்களா?

ஒரு மருத்துவராக, வெவ்வேறு மருத்துவ முறையிலிருந்து மருந்து எடுக்கும் நோயாளிக்கு உங்களின் அறிவுரை என்னவாக இருக்கும்? எடுத்துக்காட்டாக சித்தா மற்றும் அலோபதி மருந்து சேர்ந்து எடுத்துக் கொண்டால், நேரிடக்கூடிய விளைவுகள் என்ன?

நோயாளிகளை சிறப்பு மருந்துவனைக்கு செல்ல ஆலோசனை கொடுப்பீர்களா? அப்படி இருப்பின் எந்த விதமான நோயாளிகளை குறிப்பிடுவீர்கள்?

நீரிழிவு மற்றும் சிகிச்சை பற்றிய அறிவை எப்படி மேம்படுத்திக் கொள்வீர்கள்?

நீரிழிவுக்கு சிகிச்சையளிப்பதில் நீங்கள் என்னென்ன பிரச்சினைகள் / இடர்பாடுகளை எதிர்நோக்குகிறீர்கள்.

எந்தெந்த ஆதாரங்களிலிருந்து / யாரிடமிருந்து உங்களுக்கு புதிய மருந்துகளை பற்றிய தகவல்கள் கிடைக்கின்றன? எடுத்துக்காட்டாக மருத்துவ பிரதிநிதிகள்.